

Client Perspectives on the Rethinking Care Program: Report of a Telephone Survey

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Executive Summary

The Rethinking Care Project

Rethinking Care (RTC) is a program funded by the Washington State Health and Recovery Administration (HRSA) within the state Department of Social and Health Services (DSHS). The RTC Program is being carried out in collaboration with King County Care Partners (KCCP) and the Center for Healthcare Strategies (CHCS). Its purpose is to improve quality of care and reduce expenditures for Supplemental Security Income (SSI) recipients with co-occurring medical and mental health/substance abuse problems.

The RTC Program is being carried out as a randomized control trial in order to allow a rigorous evaluation of the program's impact. Approximately 1,560 eligible individuals are expected to be randomly assigned to either the RTC intervention or to a treatment-as-usual abeyance group over a two year period beginning February 1, 2009. As one part of this broader evaluation, a survey was conducted with 406 RTC clients who had been randomized to the RTC intervention in February and March 2009. This report summarizes the findings of that survey.

How the survey was carried out

Survey interviewers from the DSHS Research and Data Analysis (RDA) Division successfully interviewed 286 of the 406 clients. Sixty-one clients could not be directly interviewed (due to being deceased, in jail/prison, or unable to provide responses), resulting in a response rate of 83%. Clients who were interviewed were similar to those not interviewed except for being younger.

Characteristics of clients who participated in the survey

Approximately 57% of the 286 clients who participated in the survey were female. Respondents ranged in age from 20 to 85 with the average being 50: 56% were Caucasian, 27% were Black, and 17% were of other races/ethnicities. The EQ-5D is a standardized instrument consisting of five questions that provides a descriptive profile of health status based on clients' self report. Results of the EQ-5D indicated that approximately 73% of clients had some problems walking about, 79% had some problems with or were unable to perform their usual activities, 87% were in moderate or extreme pain/discomfort, and 76% were moderately or extremely anxious or depressed. Despite these admitted limitations, 53% said they had no problems with self-care.

Approximately 93% of clients said they had a personal doctor. At the same time, 55% said they were *always* able to get an appointment at a doctor's office or clinic as soon as they thought they needed it while another 22% said they were *usually* able to get an appointment.

Of the 286 clients who participated in this survey, 42% had agreed to participate in RTC and had completed a care plan, 12% had agreed to participate in RTC but had not completed a care plan, 13% had refused to participate in RTC, and 34% said they had never heard about the program.

Why clients said they participated or did not participate in the RTC Program

Of the 286 clients that responded to the survey, 154 said they had agreed to participate in the RTC Program (about 54% of the survey sample). These clients said they did so because the person who called them about the program was pleasant and friendly (90%) and/or because they needed help in getting their healthcare needs met (80%).

"I needed to have someone help me with my prescriptions and my doctors appointments and make for sure that I went to the right place on the right day and that I took the right medicine and the nurse assured me that she could help."

"I believed the program was a good program and I REALLY needed help with my healthcare needs. I also need help with my housing as my apartment flooded."

There were sixteen clients (about 6% of the survey sample) who agreed to participate in RTC but cut their participation short. When asked why, 13% indicated that they became ineligible for the program, 13% said they were too busy or stressed, and 13% indicated they were in the hospital, in treatment, or too ill. Client's open-ended comments were focused primarily on gaps in service that occurred because of changes in nursing staff:

"The nurse was let go by KCCP and I haven't had a new nurse assigned yet."

"My nurse quit and they never gave me a replacement nurse and the case just stopped being worked on and they finally just closed it down. They did call me to ask my permission to close it and I agreed."

The care plan is the final part of the assessment that involves the client and nurse care manager jointly developing a set of healthcare goals that are important to them. There were thirty-three clients who agreed to participate in RTC but did not complete the care plan. The predominant reasons they gave for not completing the care plan was that it was hard to schedule a time to meet with the nurse or social worker (30%), they were still working on it (27%), were too busy or stressed (21%), or were not interested in the program (21%). Open-ended comments covered a number of areas with a focus on the nurse not following up or with life's stressor's getting in the way:

"My son got into trouble that was very stressful and depressing to me and it has been hard to meet with the nurse."

"The nurse didn't do the follow through like I had hoped. Lots of phone tag and I didn't get to talk with her."

There were thirty-six clients who did not agree to participate in RTC (about 13% of the survey sample). For the most part, these clients felt they did not need the program (28%). Client's open-ended comments mostly focused on not needing the program or not being eligible for the program:

"I have a case manager who comes to see me every week from [another agency] so I don't believe I need the extra service."

"I have a lot of appointments and have everything down to a schedule, so I don't need them."

What did clients like best about the RTC Program?—open-ended responses

A total of 154 clients who agreed to participate in the RTC Program were given the opportunity to provide open-ended comments regarding what they liked best about KCCP and 136 responded (88%). Of those that responded, the majority (54%) were focused on staff, e.g., staff was friendly/helpful, the staff or program helped with their healthcare and/or medical problems, and the staff were genuinely concerned about them. The next most frequent set of responses were focused on activities (47%), e.g., the staff or program helped with their healthcare and/or medical problems, the staff helped with housing and transportation, the staff acted as a liaison with providers at medical appointments. Next in frequency were comments about the program (21%), e.g., liked 'everything', the program was generally helpful, liked the support, the staff were easy to contact and they listened. Next were comments about information (14%), e.g., the information they received, answers and explanations for their questions.

"About how personal the nurse and social worker were and how nice they were to me. They were interested in my well being."

"One of the things that really sticks out for me is that they taught me how to self-advocate. They did a lot of affirming of skills I do have and showed me how to retrain myself."

"When the nurse was with me and defended me dealing with the doctor that was not being fair - I liked that."

"The nurse went above and beyond the call of duty. She wrote letters, phone calls, and was persistent and did not give up until she won."

"The involvement and willingness to help find services and to make it possible to live at home and to get the kind of care needed."

"She has helped me get into housing that is affordable and get my life into the order that is good to live by. I am glad that she has helped so much."

What did clients like least about the program?—open-ended responses

The 154 clients who had agreed to participate in the RTC Program were given the opportunity to provide open-ended comments regarding what they liked least about KCCP and 100 responded (65%). Of those that responded, the vast majority (58%) said there was nothing they did not like. The next most frequent set of responses focused on the process or the program (23%), e.g., disappointed because their first nurse left/nobody followed up, the program ended too soon or too abruptly. The next most frequent set of responses focused

on lack of services (14%), e.g., did not get the help or services they needed. The least frequent set of responses focused on staff (8%), e.g., staff was rude/loud/bossy/judgemental/inflexible. Here are some examples of actual responses to this question:

"That the other lady didn't call me. First person was great, but nobody followed through when she left."

"It ended too soon."

"It took a bit too long to get some things rectified - she tried her hardest but some of my needs weren't getting met - I thought they would be."

"They gave me the expectation that they could help me with housing and they couldn't. Section 8 was closed and I was still in the same waiting line for HUD. I agreed to let the nurse come to my provider appointment, but she was never available to do that."

"Initially, they helped me pay for medications, but now they won't pay."

Did the RTC Program and providers have the intended impact on clients?

Goals of the RTC Program include clients getting their healthcare needs met, especially healthcare needs that were important to them; feeling empowered to take charge of their own health; and having a trusting and effective relationship with their nurse or social worker. In general, responses of clients who participated in the program indicated that the intended outcomes were being achieved:

- 92% said the healthcare goals they developed with their nurse included their most important healthcare needs
- 91% said the program helped them feel they could take charge of their health
- 90% were able to reach at least one of the healthcare goals they developed with their nurse
- 82% said the program helped them get healthcare needs met that they could not have met on their own
- 65% said the program helped them solve problems in their daily life such as housing, transportation, or finances that were stopping them from getting their health needs met.

Responses to questions about provider impacts were almost uniformly positive:

- 98% said they have/had a good, trusting relationship with the nurse or social worker
- 93% said it was easy to reach the nurse or social worker
- 91% said the nurse or social worker understood their culture
- 87% said the nurse taught them about their illness and ways to manage it
- 10% said that, when trying to help them address their needs, the nurse or social worker pushed them too hard or held them back

How satisfied were clients who participated in the RTC Program?

Client satisfaction was measured with a standard instrument, the eight-item Client Satisfaction Questionnaire (CSQ-8). In general, satisfaction levels were relatively high for the group as a whole. For example,

- 95% said if a friend were in need of similar help, they would recommend the program to them
- 93% said if they were to seek help again, they would come to the program
- 88% got the kind of service they wanted
- 83% said the services they received helped them deal more effectively with their problems
- 69% said the program met all or most of their needs

Was client satisfaction related to level of program participation?

Although overall levels of satisfaction with the program were relatively high, they were related to the extent to which clients participated in the program. For example:

- Clients with the highest level of program participation¹ had highest levels of satisfaction
 - 82% said the program met almost all or most of their needs
 - 92% rated the quality of service as excellent or good
 - 93% said services helped them deal more effectively with their problems
- Clients with intermediate levels of program participation² had mid-range levels of satisfaction
 - 63% said the program met almost all or most of their needs
 - 88% rated the quality of service as excellent or good
 - 88% said services helped them deal more effectively with their problems
- Clients with lowest levels of program participation³ had lowest levels of satisfaction
 - 30% said the program met almost all or most of their needs
 - 62% rated the quality of service as excellent or good
 - 43% said services helped them deal more effectively with their problems

Clients with low levels of participation included those who were still working with their nurse on the care plan (27%) as well as those who were having a hard time scheduling a time to meet with their nurse (30%) or who did not trust their nurse or social worker (12%). Also included in this category were clients who were no longer interested in the program (21%), were ineligible for the program (6%), or too busy/stressed (21%), or too ill (9%) to participate. Even though clients in this subgroup did not receive as high a ‘dose’ of the intervention as clients in the High and Middle subgroups, it appears that they had enough contact with the program to have formulated an opinion of how satisfied they were with that contact. In fact, for some, the lower levels of participation may have been a direct result of their lack of satisfaction. It should be noted that there were thirty-three individuals in this category, approximately 12% of those interviewed.

¹ Completed their care plan and were still participating or participated as long as they wanted (n=105)

² Completed their care plan but did not participate in the program as long as they wanted (n=16)

³ Agreed to participate in RTC but did not complete their care plan (n=33)

Was getting a doctor's appointment related to level of program participation?

Despite the fact that 97% of clients in the High participation subgroup, 88% of clients in the Middle participation subgroup, and 94% of clients in the Low participation subgroup indicated they had a personal doctor, more of the clients in the High and Middle subgroups reported always getting an appointment as soon as needed (65% and 64%, respectively) relative to the Low participation subgroup (41%). This difference was statistically significant ($p < .027$) and may be reflecting one of the benefits of RTC Program participation to clients—a somewhat higher probability of getting a doctor's appointment as soon as clients thought they needed it.

Conclusions and Recommendations

Overall, client responses could be interpreted to indicate that the RTC Program was working well with clients who agreed to participate in it and completed a care plan—42% of those surveyed. For example, an impressively high proportion of these clients reported that they achieved many of the program goals such as developing healthcare goals that were important to them (92%). In addition, a notably high proportion of these clients indicated that they had a good trusting relationship with the nurse or social worker (98%) and had high levels of satisfaction with the program—with 94% or more saying they would come back to the program if they were to seek help again. Finally, about two-thirds of these clients said they were always able to obtain a doctor's appointment as soon as they needed it. Taken together, these data suggest the program was working well with the vast majority of clients who agreed to participate and completed a care plan.

There was a small proportion of clients (6% of those interviewed) who had agreed to participate in RTC but who did not participate for as long as they wanted. For about two-thirds of the clients in this group, the disruption occurred as a result of staff changes where services were inadvertently stopped. Nonetheless, survey responses of clients in this group suggested that, they too, were achieving many of the the goals of the program.

Finally, there was a group of thirty-three clients who had not yet completed their care plan at the time of the survey interview; this represents about 12% of clients who were interviewed. Nine of these clients were still working on developing the care plan with their nurse. The remaining twenty-four clients in this group cited problems scheduling a time with the nurse, being too busy or stressed, or not interested in the program as reasons for not completing a care plan. Although it appears that these twenty-four clients have the potential of becoming lost to the program, they represent a relatively small (8%) proportion of those interviewed.

Taken together, these data suggest that the program goals were being achieved by the vast majority of clients who engaged and participated and that these clients were, for the most part, very satisfied with the RTC Program. There were, however, approximately 47% of clients interviewed who did not engage and/or participate in the program. Included in this 47% were almost 13% who declined participation in the program and 34% who said they had never heard about the RTC program. In establishing any new program, it is expected that there will be clients who decline participation. However, it is not clear why 34% said they never heard of the program. It would be important to follow-up in a subsequent study to determine what happened in these cases as they represent an important lost opportunity to the program.

Based on these conclusions, we suggest a number of recommendations for consideration.

- The program appears to be achieving success with the vast majority of clients who engaged and participated. This population, by definition, has multiple co-occurring conditions which make them a very complex and difficult group to treat. For example, they are known to use a disproportionate amount of state-funded healthcare resources, have a high rate of disability, are at high risk for treatment non-adherence, and have a high probability of premature death.⁴ They frequently migrate back and forth between multiple, disconnected systems of care, including psychiatric inpatient units, emergency rooms, community health clinics, jails, psychiatric hospitals, other medical hospitals, and substance abuse clinics.⁵ Thus, the success that was revealed in client's survey responses is noteworthy. Because such success is unusual, we recommend that the program document the intervention protocol in enough detail that it can be disseminated to and potentially adopted by other programs, states, and interested parties.
- We also suggest that RTC Program staff consider compiling 'success stories' of clients who achieve success in the program. Such stories nicely complement the quantitative data and can provide a potentially compelling 'story' to a variety of stakeholders.
- Although small in number, there were nonetheless some clients who did not receive RTC Program services in the manner intended. This would include clients whose participation in the RTC program ended before they wanted it to as well as those who still had not developed a care plan with their nurse. Clearly, many reasons for such gaps in service may be beyond the control of program staff. There were a number of cases, however, where it appeared that RTC staff may have been in a position to potentially avert such problems, such as when there were staff changes. This appears to be a vulnerable transition that could benefit from future examination.
- Most difficult to explain are why a full third of clients interviewed in the survey said they never heard of the program. We wondered whether this was due simply to start-up or if there were other factors that systematically led to this problem. We think this would be an important area of study in order to provide an understanding of what steps could be taken to change it.
- We also recommend that this survey be repeated later in the project when enrollment is complete in order to get the full picture of client perceptions once the program is stabilized. This would also allow us to better distinguish start-up effects from those that are enduring.

⁴ Mancuso, D., Nordland, D., and Felver, B. (2004). *Emergency room use patterns in Washington State Medicaid Recipients*. Olympia, WA: Department of Social and Health Services.

Institute of Medicine (2000). *America's health care safety net: Intact but endangered*. Washington, D.C.: National Academy Press. 281.

⁵ Commission, P.N.F. (2003). *Achieving the promise: transforming mental health care in America*. Washington, DC: Department of Health and Human Services (DHHS).

- The survey response rate of 83% that was reported for this study is extraordinary, especially with a population that is known to be difficult to reach. We strongly recommend that the RDA team consider writing up and publishing the methods they used for contacting clients and for engaging them in the survey so that other states and programs can learn from them.

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I. Introduction and Overview

Rethinking Care (RTC) is a program funded by the Washington State Health and Recovery Services Administration (HRSA) within the state Department of Social and Health Services (DSHS). The RTC Program is being carried out in collaboration with King County Care Partners (KCCP) and the Center for Healthcare Strategies (CHCS). Its purpose is to improve quality of care and reduce expenditures for Supplemental Security Income recipients with co-occurring medical and mental health/substance abuse problems.

The RTC Program is being carried out as a randomized control trial in order to allow a rigorous evaluation of the program's impact. Approximately 1,560 eligible individuals are expected to be randomly assigned to either the RTC intervention or to a treatment-as-usual abeyance group over a two year period beginning February 1, 2009. As part of this broader evaluation, a survey was conducted with 406 RTC clients who had been randomized to the RTC intervention in February and March 2009. This report summarizes the findings of that survey.

The client survey was designed to address a number of questions including:

- What reasons did clients give for initially agreeing to participate in the RTC Program? Continuing to participate? What benefits did they perceive they received?
- What reasons did clients give for refusing to enroll in the program? Leaving the program early?
- How satisfied were clients with the RTC Program? Did satisfaction differ for clients with different levels of program participation?

II. A Description of the Survey and the Respondents

In this section we describe how the survey was carried out and characteristics of clients who participated in the survey. The interested reader can find more detail in Appendix A, Technical Notes.

How was the survey carried out?

Survey interviewers from the DSHS Research and Data Analysis (RDA) Division attempted to interview 406 clients who had been randomized to the RTC intervention in February and March 2009. They successfully interviewed 286 individuals, resulting in a conservatively calculated response rate of 70%. When, however, clients who were not reachable were removed from the denominator [such as clients who were deceased (n=27), in jail/prison (n=3), or unable to provide responses (n= 31)], the response rate rose to 83%.

It is possible that the 286 who provided survey responses may have been more functional and/or in better health than those who did not. However, analyses of characteristics of these two groups indicated only one difference between them: Clients who were interviewed appeared similar to those not interviewed except for being younger. Please see Appendix A for more details regarding survey methodology and Appendix C for a copy of the survey.

Characteristics of clients who participated in the survey

Of the 286 clients who participated in this survey, 42% had agreed to participate in RTC and had completed a care plan, 12% had agreed to participate in RTC but had not completed a care plan, 13% had refused to participate in RTC, and 34% said they had never heard about the program (See Appendix B).

Approximately 57% of the 286 clients who participated in the survey were female. Respondents ranged in age from 20 to 85 with the average age being 50; 56% were Caucasian, 27% were Black, and 17% were other; 95% had evidence of mental illness—48% with high levels of mental illness and 47% with low levels; 47% had evidence of a need for chemical dependency treatment; and 43% had co-occurring disorders involving mental illness and chemical dependency.

A risk score was available for each respondent⁶. Only clients with a risk score 50% or more above the average level of risk for this population were eligible for inclusion in the RTC Program. Risk scores for the survey sample ranged from 1.5 to 15.8; the average risk score for respondents was 2.38 compared to an average risk score of 1.0 for the Medicaid fee-for-service population.

The EQ-5D⁷ is a standardized instrument consisting of five questions designed to provide a descriptive profile of health status based on clients' self report. Most clients admitted to some problems walking about, some problems performing their usual activities, being in moderate or extreme pain or discomfort, and being moderately or extremely anxious or depressed. Despite these admitted limitations, the majority said they had no problems with self care. These responses are summarized in Table 1 below:

Table 1. Health Status of Survey Respondents: Client Responses to the EQ-5D (n=286)

	n	%
What statement best describes your mobility?		
I have no problems walking about	58	20
I have some problems walking about	208	73
I am confined to bed	17	6
Missing	3	
What statement best describes your self-care?		
I have no problems with self care	151	53
I have some problems washing or dressing myself	108	38
I am unable to wash or dress myself	25	9
Missing	2	
What statement best describes your usual activities (e.g. work, study, housework, family, or leisure activities)?		
I have no problems with performing my usual activities	60	21
I have some problems with performing my usual activities	164	58
I am unable to perform my usual activities	59	21
Missing	3	

⁶ The risk score was calculated to reflect the predicted relative amount of Medicaid resources needed in the future using patient-specific demographic, diagnostic, and pharmaceutical data combined with nationally recognized algorithms.

⁷ <http://www.euroqol.org/>

What statement best describes your pain or discomfort?		
I have no pain or discomfort	37	13
I have moderate pain or discomfort	136	48
I have extreme pain or discomfort	110	39
Missing	3	
What statement best describes your anxiety or depression?		
I am not anxious or depressed	70	25
I am moderately anxious or depressed	132	47
I am extremely anxious or depressed	81	29
Missing	3	

Clients were also asked if they had a personal doctor --93% answered they did. As a follow-up question, they were asked how often they were able to get an appointment for their healthcare at a doctor's office or clinic as soon as they thought they needed it. Here, the majority (55%) said 'always' and 22% said, 'usually'. These responses are summarized in Table 2 below:

Table 2. Questions about Personal Doctors and Appointments with Doctors (n=286)

	n	%
A personal doctor is one you would see if you need a check-up, want advice about a health problem, or get sick or hurt. Do you have a personal doctor?		
Yes	265	93
No	20	7
Missing	1	
In the last six months, not counting the times you needed care right away, how often did you get an appointment for your healthcare at a doctor's office or clinic as soon as you thought you needed?		
Always	150	55
Usually	60	22
Sometimes	55	20
Never	9	3
Missing	12	

III. What Did We Learn about Clients Who Agreed to Participate in the Rethinking Care Project and Those That Did Not?

Of the 286 clients that responded to the survey, 154 had agreed to participate in the RTC Program ($154/286 = 54\%$), thirty-six had refused to participate in RTC ($36/286 = 13\%$), and ninety-six claimed they had never heard of the program ($96/286 = 34\%$)—see Appendix B. For purposes of this analysis, we combined clients who refused to participate with those who never heard of the program into one group, “non-participants”.

Characteristics of clients who agreed to participate in RTC versus those that did not

Clients who agreed to participate in the RTC Program were more likely to be women (63% of participants versus 51% of non-participants). Also, participants were more likely to be black (32% versus 21% of non-participants) and less likely to be of an “other” race (neither white nor black; 13% versus 23% of non-participants). See Appendix A for a more detailed comparison of RTC Program participants and non-participants.

There were few other differences between these groups. Their other demographic characteristics, mental health/substance abuse diagnoses, risk scores and EQ-5D responses were very similar (See Appendix A). Almost all said they had a personal doctor (95% of participants and 90% of non-participants—not significantly different).

Reasons for participating

Survey respondents were asked why they agreed to participate in the RTC Program (n=154). A key factor was the person who called them--most (90%) said they agreed because the person who called to tell them about the program was friendly and 79% said it was because the person that called convinced them it would be a good thing to do. Approximately 80% said they needed help in getting their healthcare needs met. The lowest proportion (58%) said it was because they wanted the \$10 Safeway certificate. These responses are summarized in Table 3 below:

Table 3. Reasons Clients Agreed to Speak to a RTC Program Nurse or Social Worker (n=154)

	n	%
The person who called to tell me about the program was pleasant and friendly	139	90
I needed help in getting my healthcare needs met	123	80
The person who called convinced me it would be a good thing to do	122	79
I wanted the \$10 Safeway certificate	89	58

The 154 clients who had agreed to participate in the RTC Program were given the opportunity to provide open-ended comments regarding their reasons for agreeing to talk to a nurse or social worker. The full set of these comments are included in Appendix E1. In brief, of the 154 respondents asked this question, 95 (62%) provided responses. Of those that responded, 31% said they needed help with their medical problems, 20% said they needed help, and 13% said they wanted help with housing. Here are a few illustrative comments:

"I needed to have someone help me with my prescriptions and my doctors appointments and make for sure that I went to the right place on the right day and that I took the right medicine and the nurse assured me that she could help."

"Well, in 2006 I suffered a very serious illness which left me disabled with several chronic conditions. I believe that the more contact I have with healthcare providers, the better off I am."

"I believed the program was a good program and I REALLY needed help with my healthcare needs. I also need help with my housing as my apartment flooded."

"I was homeless and I needed a place to stay that was safe."

"I needed the HELP."

"I had some fears about life expectancy and I was looking for help."

"They said they could help me with my chronic health issues and housing, etc."

"They could talk to me about my medications and problems with my legs."

Why some clients cut their participation in RTC short

There were sixteen clients who cut their participation in RTC short. Although not all sixteen endorsed a response to this question, those that did indicated that they became ineligible for the program (13%), were too busy or stressed (13%), or were in the hospital, in treatment, or too ill (13%). These responses are summarized in Tables 4 and 5 below:

Table 4. Reasons You Did Not Get Help for As Long As You Wanted (n=16)

	n	%
I became ineligible for the program	2	13
I was too busy or stressed	2	13
I was in the hospital, in treatment, or too ill	2	13
I didn't need it any more	1	6
I was unhappy with the program	1	6

Table 5. Problems That Stopped You from Getting Help as Long As You Wanted (n=16)

	n	%
No phone or limited access to a phone	1	6
A physical or mental disability like deafness, immobility, or memory problems	1	6
Transportation problems	0	0
Child care problems	0	0
Homelessness or moving a lot	0	0
They didn't understand my language or culture	0	0

A total of sixteen clients were given the opportunity to provide open-ended comments regarding their reasons for cutting their participation in RTC short. The full set of these comments are included in Appendix E2. In brief, of the sixteen respondents asked this question, twelve responded (75%). Of those that responded, 67% said the reason they stopped getting help as long as they wanted was because their first nurse left and their replacement nurse never followed up. Here are some examples of their full responses:

"The nurse was let go by KCCP and I haven't had a new nurse assigned yet."

"My nurse quit and they never gave me a replacement nurse and the case just stopped being worked on and they finally just closed it down. They did call me to ask my permission to close it and I agreed."

Why no care plan?

The care plan is the final part of the assessment that involves the client and nurse care manager jointly developing a set of healthcare goals that are important to them both. There were 33 clients who agreed to participate in RTC but did not complete the care plan. Predominant reasons clients gave for not completing the care plan was that it was hard to schedule a time to meet with the nurse or social worker (30%), they were still working on it (27%), were too busy

or stressed (21%), or they decided they were not interested in the program (21%). These responses are summarized in Tables 6 and 7 below:

Table 6. Why Clients May Not Have Finished Developing a Set of Healthcare Goals That Were Important to Both the Client and Their Nurse (n=36)

	n	%
It was hard to schedule a time to meet with the nurse or social worker	10	30
My nurse and I are still working together on developing a set of healthcare goals that are important to me	9	27
I was too busy or stressed	7	21
I decided I wasn't interested in the program	7	21
I didn't trust the nurse or social worker	4	12
I was in the hospital, in treatment, or too ill	3	9
I became ineligible for the program	2	6

Table 7. Problems that Made it Hard to Finish Developing a Set of Healthcare Goals that Were Important to Both the Client and Their Nurse (n=36)

	n	%
Homelessness or moving a lot	6	18
Transportation problems	3	9
Problems because of a physical or mental disability like deafness, immobility, or memory problems	3	9
No phone or limited access to a phone	2	6

A total of thirty-three clients were given the opportunity to provide open-ended comments regarding their reasons for not finishing developing a set of healthcare goals. The full set of these comments are included in Appendix E3. In brief, of the thirty-three clients asked this question, twenty-two responded (67%). Of those that responded, 27% said the nurse did not follow up with them, 23% said life stressors got in the way, 18% did not remember if they set up any goals, and 18% said they didn't need the program.

"The nurse didn't do the follow through like I had hoped. Lots of phone tag and didn't get to talk with her."

"I have not heard from the nurse in months and I do not know if I am still on the program."

"Medical issues and not being able to get around. Also have mental issues."

"I was homeless and unable to get together with the nurse or social worker."

"My son got into trouble that was very stressful and depressing to me, and it has been hard to meet with the nurse."

"They didn't have the services I was looking for and my mother does the things that the program would be able to provide."

Reasons for NOT participating in RTC

There were thirty-six clients who did not agree to participate in the RTC Program. The predominant reason they gave for not participating was that they did not need the program, that they were already happy with their healthcare (28%). These responses are summarized in Tables 8 and 9 below:

Table 8. Reasons You Decided Not to Talk to a Nurse or Social Worker (n=33)

	n	%
I didn't need the program; I was already happy with my healthcare	10	28
I was too busy or stressed	4	11
I did not want to answer lots of personal questions or have someone in my home	4	11
I was in the hospital, in treatment, or too ill	3	8
I had trouble getting in touch with each them	2	6

Table 9. Problems that Would Have Made It Hard for You to Be in the Program (n=33)

	n	%
Problems because of a physical or mental disability like deafness, immobility, or memory problems	3	8
Transportation problems	2	6
They did not understand my language or culture	2	6
Homelessness or moving a lot	1	3

A total of thirty-six clients were given the opportunity to provide open-ended comments regarding their reasons for not talking with a nurse or social worker. The full set of these comments are included in Appendix E4. In brief, of the thirty-six clients asked this question, ten responded (28%). Of those that responded, 30% said they did not need the program, and 30% said they were not eligible for the program. Here are some illustrative comments:

"I have a case manager who comes to see me every week from [another agency] so I don't believe I need the extra service."

"I have a lot of appointments and have everything down to a schedule, so I didn't need them."

"N/A, not eligible as lives in an assisted living facility."

IV. Did the RTC Program and Providers Have the Intended Impact on Clients?

Goals of the RTC Program include clients getting their healthcare needs met, especially healthcare needs that were important to them; feeling empowered to take charge of their own health; and having a trusting and effective relationship with their nurse or social worker.

Clients who participated in the program (n=121) were asked about their experience related to these goals. *In general, their responses indicated that the intended outcomes were achieved.* For example, with respect to program outcomes, 92% of respondents indicated that the set of healthcare goals they developed with their nurse included their most important healthcare needs, 91% said the program helped them feel they could take charge of their health, 90%

indicated they were able to reach at least one of the healthcare goals they established with their nurse, and 82% indicated that the program helped them get healthcare needs met that they could not have met on their own. In contrast, 65% said the program helped them solve problems in their daily life such as housing, transportation, or finances that were stopping them from getting their health needs met.

Responses to questions about provider impacts were also universally positive. For example, 98% of respondents indicated that had a good, trusting relationship with their nurse/social worker, 93% indicated it was easy to reach their nurse/social worker, 91% indicated their nurse/social worker understood their culture, 90% indicated that their nurse/social worker did not push too hard or hold them back when trying to address their needs, and 87% indicated that their nurse taught them about their illness and ways to manage it. These responses are summarized in Tables 10 and 11 below:

Table 10. Program Impact

	n	%	Missing values
The set of healthcare goals that I developed with my nurse included my most important healthcare needs.	109	92	3
The program helped me feel I can take charge of my health.	108	91	2
I was able to reach at least one of the healthcare goals I developed with my nurse	106	90	3
The program helped me get healthcare needs met that I could not have met on my own.	98	82	2
The program helped me solve problems in my daily life, such as housing, transportation, or finances, that were stopping me from getting my health needs met.	78	65	1

Table 11. Provider Impact

	n	%	Missing values
I had/have a good, trusting relationship with the nurse or social worker.	118	98	0
It was easy to reach the nurse or social worker.	111	93	2
The nurse or social worker understood my culture.	105	91	5
The nurse taught me about my illness and ways to manage it.	103	87	2
When trying to help me address my needs, the nurse or social workers pushed me too hard or held me back.	12	10	0

V. How Satisfied Were Clients Who Participated in the RTC Program?

Client satisfaction was measured with the CSQ-8. The CSQ-8 is one of the few patient satisfaction instruments that has gained wide acceptance and use among a variety of behavioral health organizations⁸. It was administered to all clients who agreed to participate in the RTC Program, whether they completed a care plan or not (n=154).

⁸ Maruish, M. E. (2002). *Psychological Testing in the Age of Managed Health Care*. Mahwah, N.J.: Lawrence Erlbaum and Associates,

Overall satisfaction levels

In general, satisfaction levels were relatively high for the group as a whole. For example, 95% of respondents said they would recommend the program to a friend who was in need of similar help, 93% said they would come back to the program if they were to seek help again, 88% said they received the kind of service they wanted from the program, 86% rated the quality of service they received as excellent or good, 86% were mostly or very satisfied with the amount of help they received, and 83% said the program helped them deal more effectively with their problems. The exception to these uniformly high ratings was the question that asked the extent to which the program met their needs—in this case 69% indicated that almost all or most of their needs had been met by the RTC Program. These responses are summarized in Table 12 below. Responses were collapsed from four to two categories for each item, but the full set of responses is available in Appendix F.

Table 12. Client Satisfaction as Measured by the CSQ-8 (n=154)

	n	%
How would you rate the quality of service you have received?		
Excellent or good	129	86
Fair or poor	21	14
Missing	4	
Did you get the kind of service you wanted?		
No, definitely or no, not really	18	12
Yes, generally or yes, definitely	131	88
Missing	5	
To what extent has our program met your needs?		
Almost all or most of my needs have been met	104	69
Only a few or none of my needs have been met	46	31
Missing	4	
If a friend were in need of similar help, would you recommend our program to him or her		
No, definitely not or no, I don't think so	8	5
Yes, I think so or yes, definitely	142	95
Missing	4	
How satisfied were you with the amount of help you have received?		
Quite dissatisfied, indifferent, or mostly dissatisfied	20	14
Mostly or very satisfied	126	86
Missing	8	
Have the services you received helped you deal more effectively with your problems?		
Yes, they helped a great deal or yes, they helped	122	83
No, they really didn't help or no, they seemed to make things worse	25	17
Missing	7	
In an overall general sense, how satisfied are you with the service you received?		
Very or mostly satisfied	128	85
Indifferent or mildly satisfied or quite dissatisfied	22	15
Missing	4	
If you were to seek help again would you come back to our program?		
No, definitely not or no, I don't think so	10	7
Yes, I think so or yes, definitely	140	93
Missing	4	

What did clients like best about the program?—open-ended responses

The 154 clients who agreed to participate in the RTC Program were given the opportunity to provide open-ended comments regarding what they liked best about KCCP. The full set of

these comments are included in Appendix E5. In brief, of the 154 clients asked this question, 136 responded (88%). Of those that responded, the majority (54%) were focused on staff, e.g., the staff was friendly/helpful, the staff or program helped with their healthcare and/or medical problems, and the staff were genuinely concerned about them. The next most frequent set of responses were focused on activities (47%), e.g., the staff or program helped with their healthcare and/or medical problems, the staff helped with housing and transportation, the staff acted as a liaison with providers at medical appointments. Next in frequency were comments about the program (21%), e.g., liked 'everything', the program was generally helpful, liked the support, the staff were easy to contact and they listened. Next were comments about information (14%), e.g., the information they received, answers and explanations for their questions. Here are some examples of clients' specific responses to this question:

"About how personal the nurse and social worker were and how nice they were to me. They were interested in my well being."

"Their follow-up, friendliness and concern. They knew about my case and did not call up blind."

"One of the things that really sticks out for me is that they taught me how to self-advocate. They did a lot of affirming of skills I do have and showed me how to retrain myself."

"I like it because they tell me things that I might not like to hear but I need to hear."

"I like the fact that they told me about things that I didn't know about. Gave me good information about my rights and I feel more confident."

"They explained things very well to me and I am very satisfied with their response."

"When the nurse was with me and defended me dealing with the doctor that was not being fair - I liked that."

"The nurse asked my doctor stuff that I could not ask and made sure that I got the information that I needed."

"They came out to my house at the time that I had no doctor and couldn't get my medicine. Now I have both."

"I liked that they were very friendly and non-judgmental and they were very helpful when I presented my problems."

"That the worker showed some genuine concern. She more or less made sure I made my appointments and met me at whatever I was supposed to."

"The nurse went above and beyond the call of duty. She wrote letters, phone calls, and was persistent and did not give up until she won."

"The involvement and willingness to help find services and to make it possible to live at home and to get the kind of care needed."

"I like the professionalism of the nurse. I like the personality of the nurse. I like the knowledge of the nurse."

"I think the kindness of the social worker, and her interest in me. She went out of her way to bring some books to read."

"She has helped me get into housing that is affordable and get my life into the order that is good to live by. I am glad that she has helped so much."

"Just gave me some helpful information and I now have doctors near where I live"

"It helped me with my medicine and my doctor visits. My medicine is now given to me in bubble wrap and it makes it much easier to take."

"It's comforting to feel that there is someone there to help when you get caught up in things that are happening that you don't understand."

What did clients like least about the program?—open-ended responses

The 154 clients who had agreed to participate in the RTC Program were given the opportunity to provide open-ended comments regarding what they liked least about KCCP. The full set of these comments are included in Appendix E6. In brief, of the 154 clients asked this question, 100 responded (65%). Of those that responded, the vast majority (58%) said there was nothing they did not like. The next most frequent set of responses focused on the process or the program (23%), e.g., disappointed because their first nurse left/nobody followed up, the program ended too soon or too abruptly. The next most frequent set of responses focused on lack of services (14%), e.g., did not get the help or services they needed. The least frequent set of responses focused on staff (8%), e.g., staff were rude/loud/bossy/judgemental/inflexible. Here are some actual responses to this question:

"I did not like the idea that you built a relationship with a person (nurse or social worker) and then all of a sudden that stopped and you never heard anything for a long time."

"That the other lady didn't call me. First person was great, but nobody followed through when she left."

"It ended too soon."

"I was upset that it ended for me."

"It's the fact of the doctors trying to agree in my case. I take a lot of medications and

I have talked to them that some of the medications are not good for me. They had the possibility of helping me but really didn't help me. Because, in my case, the doctors complained that I take too much pain medication. I have been in pain for 16 years. I told them that what takes away my pain is marijuana. They won't prescribe that since they seem [to think] I take too much meds. I am now going through a third party to get the marijuana that I need. The extreme pain makes me go to the emergency room and I need the pain medication!"

"Sometimes, I did not want the nurse to come to my appointments, but she did."

"I wish I would have had more visits from the nurse. There was not enough of them."

"It took a bit too long to get some things rectified - she tried her hardest but some of my needs weren't getting met - I thought they would be."

"Not being able to have the nurse keep up with the seriousness of the illness that I had."

"They gave me the expectation that they could help me with housing and they couldn't. Section 8 was closed and I was still in the same waiting line for HUD. I agreed to let the nurse come to my provider appointment, but she was never available to do that."

"Initially, they helped me pay for medications, but now they won't pay."

"The nurse is a little bossy and loud."

Was client satisfaction related to level of program participation?

Although overall levels of satisfaction with the program were relatively high, they were related to the extent to which clients participated in the program. Specifically, clients with the highest level of program participation [i.e., who completed their care plan and who were still participating/or participating as long as they wanted ("High")] had the highest levels of satisfaction, followed by clients who had an intermediate level of program participation [i.e., completed their care plan but did not participate in the program as long as they wanted ("Middle")], followed by clients with the lowest level of participation [i.e., clients who agreed to participate but who did not complete their care plan ("Low")] being least satisfied.

For example:

- Clients with the highest level of program participation⁹ had highest levels of satisfaction
 - 82% said the program met almost all or most of their needs
 - 92% rated the quality of service as excellent or good
 - 93% said services helped them deal more effectively with their problems

⁹ Completed their care plan and were still participating or participated as long as they wanted (n=105)

- Clients with intermediate levels of program participation¹⁰ had mid-range levels of satisfaction
 - 63% said the program met almost all or most of their needs
 - 88% rated the quality of service as excellent or good
 - 88% said services helped them deal more effectively with their problems
- Clients with lowest levels of program participation¹¹ had lowest levels of satisfaction
 - 30% said the program met almost all or most of their needs
 - 62% rated the quality of service as excellent or good
 - 43% said services helped them deal more effectively with their problems.

Clients with low levels of participation included those who were still working with their nurse on the care plan (27%) as well as those who were having a hard time scheduling a time to meet with their nurse (30%) or who did not trust their nurse or social worker (12%). Also included in this category were clients who were no longer interested in the program (21%), were ineligible for the program (6%), or too busy/stressed (21%), or too ill (9%) to participate. Even though clients in this subgroup had not received as high a ‘dose’ of the intervention as clients in the “High” and “Middle” subgroups, it appears that they had enough contact with the program to have formulated an opinion of how satisfied they were with that contact. In fact, for some, the lower levels of participation may have been a direct result of their lack of satisfaction. It should be noted that there were thirty-three individuals in this category, approximately 12% of those interviewed.

A more complete summary of client satisfaction by level of program participation is contained in Table 13. Responses were collapsed from four to two categories for each item. Appendix F contains a table with full responses.

¹⁰ Completed their care plan but did not participate in the program as long as they wanted (n=16)

¹¹ Agreed to participate in RTC but did not complete their care plan (n=33)

Table 13. Client Satisfaction as Measured by the CSQ-8 for Clients with High, Medium, and Low Participation Levels in the RTC Program

Variable	Participation Level						Overall n =154	p- value ¹²	
	High n = 105		Middle n = 16		Low n = 33				
	n	%	n	%	n	%			
How would you rate the quality of service you have received?									<.0005
Excellent or good	97	92	14	88	18	62	129	86	
Fair or poor	8	8	2	13	11	38	21	14	
Missing	0		0		4		4		
Did you get the kind of service you wanted?									<.0005
No, definitely or no, not really	7	7	1	7	10	33	18	12	
Yes, generally or yes, definitely	97	93	14	93	20	67	131	88	
Missing	1		1		3		5		
To what extent has our program met your needs?									<.0005
Almost all or most of my needs have been met	85	82	10	63	9	30	104	69	
Only a few or none of my needs have been met	19	18	6	38	21	70	46	31	
Missing	1		0		3		4		
If a friend were in need of similar help, would you recommend our program to him or her?									<.0005
No, definitely not or no, I don't think so	1	1	0	0	7	23	8	5	
Yes, I think so or yes, definitely	103	99	16	100	23	77	142	95	
Missing	1		0		3		4		
How satisfied were you with the amount of help you have received?									<.0005
Quite dissatisfied, indifferent, or mostly dissatisfied	6	6	1	7	13	46	20	14	
Mostly or very satisfied	98	94	13	93	15	54	126	86	
Missing	1		2		5		8		
Have the services you received helped you deal more effectively with your problems?									<.0005
Yes, they helped a great deal or yes, they helped	96	93	14	88	12	43	122	83	
No, they really didn't help or no, they seemed to make things worse	7	7	2	13	16	57	25	17	
Missing	2		0		5		7		
In an overall general sense, how satisfied are you with the service you received?									.003
Very or mostly satisfied	95	91	13	81	20	67	128	85	
Indifferent, mildly satisfied or quite dissatisfied	9	9	3	19	10	33	22	15	
Missing	1		0		3		4		
If you were to seek help again would you come back to our program?									<.0005
No, definitely not or no, I don't think so	2	2	1	6	7	23	10	7	
Yes, I think so or yes, definitely	101	98	15	94	24	77	140	93	
Missing	2		0		2		4		

¹² p-value calculated using Fisher's exact test

We wondered whether level of participation in the program may have been associated with particular demographic or other characteristics. To examine this, we conducted comparisons between High, Middle, and Low subgroups on a number of variables that we had available to us. A summary of these comparisons is located in Appendix G. Essentially, the only variable on which these groups differed on was the question of, *‘In the last six months, how often did you get an appointment for your healthcare at a doctor’s office or clinic as soon as you thought you needed it?’*

Did getting a doctor’s appointment vary in groups with different levels of participation?

Despite the fact that 97% of clients in the High participation subgroup, 88% of clients in the Middle participation subgroup, and 94% of clients in the Low participation subgroup indicated they had a personal doctor, more of the clients in the High and Middle subgroups reported always getting an appointment as soon as needed (65% and 64%, respectively) relative to the Low participation subgroup (41%). This difference is statistically significant ($p < .027$) and may be reflecting one of the benefits of RTC Program participation to clients—a somewhat higher probability of getting a doctor’s appointment as soon as clients thought they needed it. These responses are summarized in Table 14 below:

Table 14. Access to Healthcare for Clients with High, Medium, and Low Participation Levels in the RTC Program

	Participation Level						Overall n =154	p- value ¹³
	High n = 105		Middle n = 16		Low n = 33			
	n	%	n	%	n	%		
A personal doctor is one you would see if you need a check-up, want advice about a health problem, or get sick or hurt. Do you have a personal doctor?								NS
No	3	3	2	13	2	6	7	5
Yes	102	97	14	88	31	94	147	95
In the last six months, not counting the times you needed care right away, how often did you get an appointment for your healthcare at a doctor's office or clinic as soon as you thought you needed?								.027
Never	2	2	0	0	4	13	6	4
Sometimes	20	19	4	29	6	19	30	20
Usually	15	14	1	7	9	28	25	17
Always	68	65	9	64	13	41	90	60
Missing	0		2		1		3	

¹³ p value calculated using Fisher’s exact test

VI. Conclusions & Recommendations

Overall, client survey responses could be interpreted to indicate that the RTC Program was working well with clients who agreed to participate in it and completed a care plan—42% of those surveyed. An impressively high proportion of these clients reported that they achieved many of the program goals such as developing healthcare goals that were important to them (92%), saying that the program helped them feel they could take charge of their health (91%), and stating that they reached at least one of their healthcare goals (90%). In addition, a notably high proportion of these clients indicated that they had a good trusting relationship with the nurse or social worker (98%), that it was easy to reach their nurse/social worker (93%), and that the nurse/social worker understood their language and culture (91%). Clients who agreed to participate in the program and completed a care plan also had high levels of satisfaction with the program—with 94% or more saying they would come back to the program if they were to seek help again and almost 100% saying they would recommend the RTC Program to a friend in need of similar help. Taken together, these data suggest the program was working well with the vast majority of clients who agreed to participate and completed a care plan.

There was a small proportion of clients (6% of those interviewed) who had agreed to participate in RTC but who did not participate for as long as they wanted. For about half the clients in this group, the disruption occurred as a result of staff changes where services were inadvertently stopped. Nonetheless, survey responses of clients in this group suggested that they, too, were achieving many of the goals of the program.

Finally, there was a group of thirty-three clients who had not yet completed their care plan at the time of the survey interview; this represents about 12% of clients who were interviewed. Nine of these clients were still working on developing the care plan with their nurse. The remaining twenty-four clients in this group cited problems scheduling a time with the nurse, being too busy or stressed, or not interested in the program as reasons for not completing a care plan. Although it appears that these twenty-four clients have the potential of becoming lost to the program, they represent a relatively small (8%) proportion of those interviewed.

Taken together, these data suggest that the program goals were being achieved by the vast majority of clients who engaged and participated and that these clients were, for the most part, very satisfied with the RTC Program. There were, however, approximately, 47% of clients interviewed who did not engage and/or participate in the program. Included in this 47% were almost 13% who declined participation in the program and 34% who said they had never heard about the RTC program. In establishing any new program, it is expected that there will be clients who decline participation. However, it is not clear why 34% said they never heard of the program. It would be important to follow-up in a subsequent study to determine what happened in these cases as they represent an important lost opportunity to the program.

Based on these conclusions, we suggest a number of recommendations for consideration.

- The program appears to be achieving success with the vast majority of clients who engaged and participated. This population, by definition, has multiple co-occurring conditions which make them a very complex and difficult group to treat. For example,

they are known to use a disproportionate amount of state-funded healthcare resources, have a high rate of disability, are at high risk for treatment non-adherence, and have a high probability of premature death.¹⁴ They frequently migrate back and forth between multiple, disconnected systems of care, including psychiatric inpatient units, emergency rooms, community health clinics, jails, psychiatric hospitals, other medical hospitals, and substance abuse clinics.¹⁵ Thus, the success that was revealed in client's survey responses is noteworthy. Because such success is unusual, we recommend that the program document the intervention protocol in enough detail that it can be disseminated to and potentially adopted by other programs, states, and interested parties.

- We also suggest that RTC Program staff consider compiling 'success stories' of clients who achieve success in the program. Such stories nicely complement the quantitative data and can provide a potentially compelling 'story' to a variety of stakeholders.
- Although small in number, there were nonetheless some clients who did not receive RTC Program services in the manner intended. This would include clients whose participation in the RTC program ended before they wanted it to as well as those who still had not developed a care plan with their nurse. Clearly, many reasons for such gaps in service may be beyond the control of program staff. There were a number of cases, however, where it appeared that RTC staff may have been in a position to potentially avert such problems, such as when there were staff changes. This appears to be a vulnerable transition that could benefit from future examination.
- Most difficult to explain are why a full third of clients interviewed in the survey said they never heard of the program. We wondered whether this was due simply to start-up or if there were other factors that systematically led to this problem. We think this would be an important area of study in order to provide an understanding of what steps could be taken to change it.
- We also recommend that this survey be repeated later in the project when enrollment is complete in order to get the full picture of client perceptions once the program is stabilized. This would also allow us to better distinguish start-up effects from those that are enduring.
- The survey response rate of 83% that was reported for this study is extraordinary, especially with a population that is known to be difficult to reach. We strongly recommend that the RDA team consider writing up and publishing the methods they used for contacting clients and for engaging them in the survey so that other states and programs can learn from them.

¹⁴ Mancuso, D., Nordland, D., and Felver, B. (2004). *Emergency room use patterns in Washington State Medicaid Recipients*. Olympia, WA: Department of Social and Health Services.

Institute of Medicine (2000). *America's health care safety net: Intact but endangered*. Washington, DC: National Academy Press. 281.

¹⁵ Commission, P.N.F. (2003). *Achieving the promise: transforming mental health care in America*. Washington, DC: Department of Health and Human Services (DHHS).

Appendix A. Technical Notes

Survey Instrument

The survey was designed by Meg Cristofalo and Toni Krupski from the Center for Healthcare Improvement for Addictions, Mental Illness and Medically Vulnerable Populations (CHAMMP) in collaboration with Beverly Court from the Health and Recovery Services Administration (HRSA) of the Department of Social and Health Services (DSHS). Ms. Cristofalo wrote the survey items and constructed the skip patterns. The resulting draft survey was then reviewed and revisions suggested by Nancy Raiha, PhD, Monica Stanley, BA, and their staff at DSHS/Research and Data Analysis (RDA) Division. The final survey was the result of several rounds of reviews and revisions by the above-mentioned CHAMMP and DSHS staff.

The instrument was designed to insure that the survey completed by each respondent was customized to their specific level of participation in the Rethinking Care (RTC) Program. In addition to a customized introduction, questions were drawn from seven question sets, again, in a customized manner. For example, a client who, in the introduction, indicated they had never heard about the RTC Program only completed one question set. On the other hand, clients whose participation was more extensive could complete up to seven question sets. A flow diagram that illustrates this point is provided as Appendix B. The full survey instrument is included as Appendix C.

Interview Methods

Telephone interviews were conducted by DSHS-RDA staff. Telephone interviews began on March 17, 2010 and ended on May 6, 2010. If necessary, more than 20 attempts were made to contact each member of the sample. Before the interviews, DSHS-RDA staff sent all sample members a prior notification letter that: (a) informed the client that an interviewer would be calling, (b) assured the client that all survey data would be confidential and not personally identifiable, (c) emphasized that the interview would be voluntary and would not affect the client's status or benefits in any way, (d) included a response form and a self-addressed pre-paid envelope. See Figures 1 and 2, pages 26 and 27.

Response Rate

Survey interviewers from DSHS-RDA attempted to interview 406 clients who had been randomized to the RTC intervention in February and March 2009. They successfully interviewed 286 individuals. See Table below:

	n	%
*Completed	286	70
*Physically or cognitively unable to respond and no other respondent available; or interview completed by a collateral	29	7
Deceased	27	7
No answer - phone temporarily out of service - not accepting calls - VM not set up	20	5
*Refused	16	4
Can't find	12	3
Homeless and can't reach	6	1
Jail or prison	3	1

We have a correct address but phone is not listed anywhere - may not have one.	2	0
No phone - we have a correct address, but client has no phone	2	0
Nursing home - not able to speak to client	1	0
Out of country	1	0
Hospice	1	0
Total	406	100

*Interviewers made contact

The table above indicates that interviewers made contact with 331 individuals, resulting in a completion rate of $331/379 = 87\%$.

The response rate was conservatively calculated as 70% ($286/406 = 70\%$). When, however, we followed the convention of removing a number of clients from the denominator who were not able to be interviewed (such as clients who were deceased ($n=27$), in jail/prison ($n=3$), or unable to provide responses ($n=32$), the response rate rose to 83%.

These response rates are extraordinarily high for any survey, but are especially remarkable for a survey involving the particularly challenging population of DSHS clients. The main difficulties encountered in locating clients and completing interviews were the following:

- Many DSHS clients are transient and do not maintain a permanent residence.
- Like many other Americans, many DSHS clients block non-personal calls, screen their calls through answering machines, or use cell phones instead of residential phones.
- Most DSHS clients are low income, and a number do not have home phones. (Unlike most telephone surveys, this survey included selected respondents without residential telephones in the sample and response rate calculations.)
- A number of the clients were too sick to complete the survey, or found listening and responding too demanding.

Surveyors employed a number of measures to dramatically increase response rates.

- **Skilled staff.** The interviewer staff is comprised of highly experienced interviewers who were chosen not only for their experience, but also because they were retired DSHS employees who had spent many years locating DSHS clients as part of Quality Assurance investigations and other DSHS business. These interviewers were highly skilled at using DSHS records, the Internet and other public sources to find a client's current address and phone number.
- **Advance notice.** Before clients were contacted by phone, they received a letter explaining the survey, stressing the importance of this opportunity to provide feedback, and assuring them of confidentiality. The letter also gave them an opportunity to send in updated phone numbers and addresses.
- **Incentives.** All clients who completed the survey were sent a \$20 Safeway gift card.
- **Multiple attempts.** Interviewers attempted to reach clients at many different times, and, if necessary, made 20 or more attempts to reach each client. If an answering machine was reached, interviewers left a message asking the client or representative to call them at a toll-free number.

- **Alternate contact methods.** Clients were given a toll-free number so that they could call in and complete the survey. Interviewers also worked with caseworkers, relatives and neighbors to make arrangements to administer the survey to clients at convenient times and locations. These strategies were particularly useful for clients who did not have a home phone.
- **Languages.** If selected clients spoke languages other than English, *staff* administered the telephone survey in a three-way conversation with interpreters from Pacific Interpreters. The survey was administered in fourteen languages: English, Somali, Amharic, Cambodian (Khmer), Cantonese, Farsi, Laotian, Oromo, Punjabi, Russian, Serbo-Croatian, Spanish, Urdu, and Vietnamese.

Differences between Clients Included and Not Included in Survey Dataset

Of 406 potential survey responders, 312 completed the survey. Twenty-six of the 312 were completed by a collateral (such as a caregiver or relative) and, for this reason, were removed from the survey dataset, for a final *n* of 286 completed surveys.

Survey participants who were included in the dataset were similar to those not included on all variables except age. In this one case, clients not in the survey dataset were older than those in the dataset. A complete set of variables on which these groups were compared is included below.

Comparison of Clients Included and Not Included in Survey Dataset¹⁶

	In Survey Dataset <i>n</i> = 286		Not in Survey Dataset <i>n</i> = 93		Overall <i>n</i> = 379		p-value ¹⁷
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Gender							NS ¹⁸
Male	122	43	49	53	171	45	
Female	164	57	44	47	208	55	
Age group							< 0.001
20-39	44	15	20	22	64	17	
40-49	82	29	15	16	97	26	
50-59	119	42	29	31	148	39	
60-85	41	14	29	31	70	18	
Race/ethnicity							NS
White	159	56	49	53	208	55	
Black	77	27	29	31	106	28	
Other	50	17	15	16	65	17	
Risk score							NS
1.5 - 1.99	129	45	41	44	170	45	
2.0 - 2.49	83	29	19	20	102	27	
2.5 and over	74	26	33	35	107	28	
Mental illness treatment need							NS
High	138	48	45	48	183	48	
Low	134	47	39	42	173	46	
None	14	5	9	10	23	6	
Substance use (SU) treatment need							NS ¹⁸
No	153	53	53	57	206	54	
Yes	133	47	40	43	173	46	
Co-occurring mental illness and SU treatment needs							NS ¹⁸
No	163	57	58	62	221	58	
Yes	123	43	35	38	158	42	
Co-occurring mental illness (high) and SU treatment needs							NS ¹⁸
No	209	73	72	77	281	74	
Yes	77	27	21	23	98	26	
Co-occurring mental illness (low) and SU treatment needs							NS ¹⁸
No	240	84	79	85	319	84	
Yes	46	16	14	15	60	16	

¹⁶ Clients who were deceased were removed from the "Not interviewed" group.

¹⁷ *p* value calculated using chi-square test, unless otherwise noted

¹⁸ *p* value calculated using Fisher's exact test

Differences between RTC Participants and Non-Participants

Among the 286 survey respondents, 154 participated in the RTC program and 132 did not. RTC participants were fairly similar to non-participants, except with respect to gender and race. Participants were more likely to be female (63% versus 51%) and of black race (32% versus 21%), and were less likely to be of an “other” race (neither black nor white, 13% versus 23%).

Comparison of RTC Participants vs. Non-participants

	RTC Participants (Groups A, B, C)		Non- participants (Groups D, E)		Overall		p-value ¹⁹
	n = 154		n = 132		n = 286		
	n	%	n	%	n	%	
Gender							.042 ²⁰
Male	57	37	65	49	122	43	
Female	97	63	67	51	164	57	
Age group							NS
20-39	23	15	21	16	44	15	
40-49	48	31	34	26	82	29	
50-59	67	44	52	39	119	42	
60-85	16	10	25	19	41	14	
Race/ethnicity							.033
White	85	55	74	56	159	56	
Black	49	32	28	21	77	27	
Other	20	13	30	23	50	17	
Risk score							NS
1.5 - 1.99999	69	45	60	45	129	45	
2.0 - 2.4999999	47	31	36	27	83	29	
2.5 and over	38	25	36	27	74	26	
Mental illness treatment need							NS
High	76	49	62	47	138	48	
Low	70	45	64	48	134	47	
None	8	5	6	5	14	5	
Substance use (SU) treatment need							NS ²⁰
No	84	55	69	52	153	53	
Yes	70	45	63	48	133	47	
Co-occurring mental illness and SU treatment need							NS ²⁰
No	89	58	74	56	163	57	
Yes	65	42	58	44	123	43	
Co-occurring mental illness (high) and SU treatment need							NS ²⁰
No	115	75	94	71	209	73	
Yes	39	25	38	29	77	27	
Co-occurring mental illness (low) and SU treatment need							NS ²⁰
No	128	83	112	85	240	84	
Yes	26	17	20	15	46	16	
Would you say that in general your health is...							NS ²⁰
Excellent	4	3	1	1	5	2	
Very good	12	8	4	3	16	6	

¹⁹ p value calculated using chi-square test, unless otherwise noted

²⁰ p value calculated using Fisher's exact test

Comparison of RTC Participants vs. Non-participants Cont.

	RTC Participants (Groups A, B, C)		Non-participants (Groups D, E)		Overall		p-value ²¹
	n = 154		n = 132		n = 286		
	n	%	n	%	n	%	
Would you say that in general your health is... cont.							NS ²⁰
Good	28	18	36	27	64	22	
Fair	56	36	43	33	99	35	
Poor	53	34	46	35	99	35	
Don't know / Not sure	1	1	1	1	2	1	
Which statement best describes your self-care?							NS
I have no problems with self-care	84	55	67	51	151	53	
I have some problems washing or dressing myself	60	39	48	37	108	38	
I am unable to wash or dress myself	9	6	16	12	25	9	
Which statement best describes your usual activities (e.g. work, study, housework, family, or leisure activities)?							NS
I have no problems with performing my usual activities	36	24	24	18	60	21	
I have some problems with performing my usual activities	89	58	75	58	164	58	
I am unable to perform my usual activities	28	18	31	24	59	21	
Which statement best describes your pain or discomfort?							NS
I have no pain or discomfort	16	10	21	16	37	13	
I have moderate pain or discomfort	74	48	62	48	136	48	
I have extreme pain or discomfort	63	41	47	36	110	39	
Which statement best describes your anxiety or depression?							NS
I am not anxious or depressed	36	24	34	26	70	25	
I am moderately anxious or depressed	76	50	56	43	132	47	
I am extremely anxious or depressed	41	27	40	31	81	29	
Do you have a personal doctor?							NS ²⁰
No	7	5	13	10	20	7	
Yes	147	95	118	90	265	93	
In the last six months, not counting the times you needed care right away, how often did you get an appointment for your healthcare at a doctor's office or clinic as soon as you thought you needed?							NS ²⁰
Never	6	4	3	2	9	3	
Sometimes	30	20	25	20	55	20	
Usually	25	17	35	28	60	22	
Always	90	60	60	49	150	55	

²¹ p value calculated using chi-square test, unless otherwise noted

Analysis of Quantitative Survey Data

We received a Microsoft Excel™ file containing survey responses from RDA which had been de-identified and linked with the following information for each respective client:

- Gender
- Age group, by the following categories:
 - 20-39
 - 40-49
 - 50-59
 - 60-85
- Race, by the following categories:
 - White
 - Black
 - Other
- Risk score, by the following categories:
 - 1.5 - 1.99999
 - 2.0 - 2.4999999
 - 2.5 and over
- Flag for mental illness, by the following categories:
 - High mental illness
 - Low mental illness
 - No mental illness
- Flag for substance abuse treatment need
- Response code, by the following categories:
 - Completed survey
 - Deceased
 - No Answer - Phone Temporarily Out of Service - Not Accepting Calls - VM
 - Not Set-up
 - Refused
 - Can't Find
 - Homeless and can't reach
 - Jail or prison
 - Physically or Cognitively Unable to Respond and no other respondent available
 - We have a correct address but phone is not listed anywhere - may not have one
 - No Phone - We have a correct address, but client has NO PHONE
 - Nursing Home - Not able to speak to client
 - Out of Country
 - Hospice

Data were imported into SPSS version 18 (PASW) and re-coded from text responses (e.g., “no” or “yes”) to numerical responses. (“0” or “1”).

New “co-occurring” variables were created from the mental illness and substance abuse treatment flags, in the following combinations:

New Variables Created from Dataset

New variable	Mental illness?	Treatment for substance abuse needed?
Co-occurring mental illness and SU treatment need	Either high or low mental illness	Yes
Co-occurring mental illness (high) and SU treatment need	High mental illness only	Yes
Co-occurring mental illness (low) and SU treatment need	Low mental illness only	Yes

For Tables 12 and 13, new CSQ-8 variables were created that combined the top two responses and the bottom two responses. Satisfaction data is presented in this collapsed format within the report, while all response categories are shown in Appendix F.

All quantitative frequencies and cross-tables were generated in SPSS version 18 (PASW).

Qualitative Data

Open-ended responses were analyzed using Microsoft Excel™. Responses were read through twice, with major themes noted during each reading. Each response was then assigned one or more themes. A second reader then reviewed the themes for each question, which led to an additional grouping into fewer themes. All names of RTC staff or other individuals were removed from open-ended responses. Typos and basic grammatical mistakes were corrected within open-ended responses, as well.

Figure 1. Survey Recruitment Letter



STATE OF WASHINGTON
DEPARTMENT OF SOCIAL AND HEALTH SERVICES
RESEARCH AND DATA ANALYSIS DIVISION
P.O. Box 45204 • Olympia, Washington 98504-5204
Phone (360) 902-0707 • Fax (360) 902-0705

November 30, 2010

<Name>
<address1>

We want to hear from you! Your feedback can help us find better ways to assist people who need medical care. You are part of a group chosen to tell us how you feel about the help you may have received from the King County Care Partners Program.

Staff from the Survey Research Office will call you and others in the group chosen to participate in the study. **You decide** whether to take part. **You will not lose any DSHS services or benefits if you choose not to participate.** Your answers will be kept strictly confidential; no one who makes decisions about your benefits will know how you answered. Your name will never be used; the researchers will combine all the survey answers into one report.

It is very important that we reach everyone chosen to participate. We need a good phone number for you. Please send the gold sheet, or call **toll-free at 1-800-974-5456** to tell us the best way to reach you.



Return the attached gold sheet or call us—and complete the survey—and receive a \$20 Safeway gift card!

Funding for the gift cards is provided by a grant for the improvement of healthcare services.

We will be calling you soon to tell you more about the study, answer any questions, and ask if you want to take the short survey. **If you have already decided that you do not want to participate in this survey, please call us at 1-800-974-5456 and we'll take your name off the calling list.** Your study number is «Study».

We hope you will decide to help in this important study, if you have any questions, please call us at **1-800-974-5456**.

Sincerely,
Nancy Raiha, MSW, Ph.D.
Senior Research Manager
DSHS Research and Data Analysis

Enclosure

Figure 2. Survey Recruitment Contact Sheet

Here's How to Reach Me



Yes! I'll take the \$20 Safeway gift card

My Phone/Cell numbers:

() (Days)
() (Evenings)
() (Message)

The best time to call me (*mark all that are good*):

☐ Mornings (9-noon) ☐ Afternoon (1-4) ☐ Early Evening (5-7)
☐ Later Evening (7-9) ☐ Weekends

Do we have the right language for you?

«primary_language»

☐ Yes, it's right!
☐ No, the best language is: _____

We will mail your \$20 Safeway gift card to your address when you complete the survey.

Do we have the right address for you?

☐ Yes, it's right!
☐ No, it's not right. See correction marked below:

<Name>

<address1>

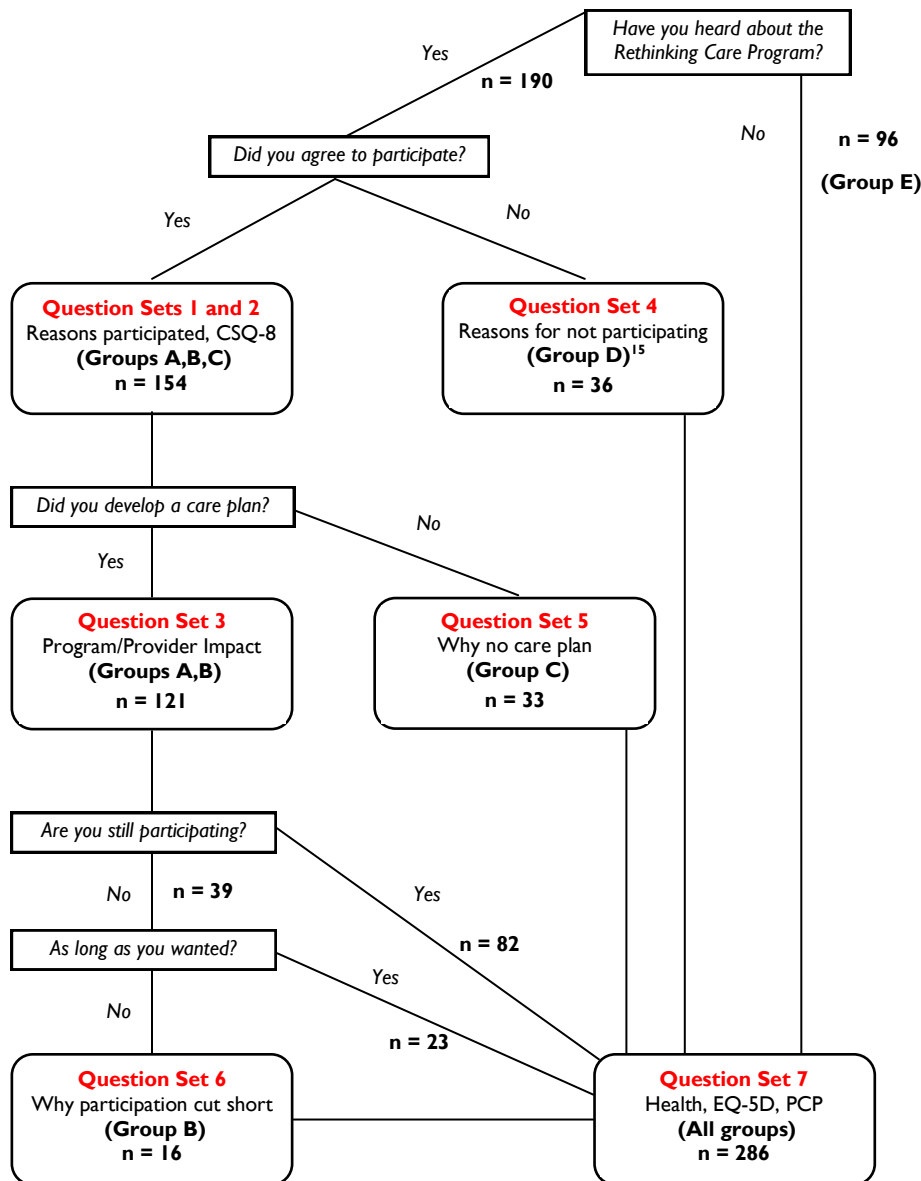
Send this gold sheet back to us in the enclosed envelope.

You won't need a stamp.

If you would rather call us to tell us how to reach you, or if you have any questions,
please call **1-800-974-5456**.

Your study number is <Study>

Appendix B. Rethinking Care Survey: Diagram of Participant Groups



Group	Description	Question Sets	N	%
A	Completed care plan, still participating or participated as long as they wanted	Demographics, 1, 2, 3, 7	105	37
B	Completed care plan, didn't participate in program as long as they wanted	Demographics, 1, 2, 3, 6, 7	16	6
C	Agreed to participate, didn't complete care plan	Demographics, 1, 2, 5, 7	33	12
D	Didn't agree to participate ²²	Demographics, 4, 7	36	13
E	Never heard about the program	Demographics, 7	96	34
		Survey Total	286	100
F	Not interviewed	Demographics	120	

²² Fifteen of the thirty-six individuals in Group D initially agreed to talk to a nurse or social worker from KCCP, but never had a conversation with them.

Appendix C. Survey Instrument

King County Care Partners Participant Survey (3/10/10)

A. Introduction

1. Hello, my name is _____ and I work at the Research Office of the Department of Social and Health Services.

Recently, DSHS sent you a letter telling you that someone would be calling you. Do you remember getting that letter?

- o Yes → CONTINUE
- o No → SKIP TO 2.

I'd like to ask you a few questions about your health and your involvement with the King County Care Partners Program. The survey should take 10 minutes or less. If there are any questions you don't want to answer, just let me know and we'll skip them. We'd also like to give you a \$20 Safeway gift card for gas or food just to say, thank you, for doing the survey.

→ GO TO 3.

2. The letter explained that your feedback can help us find better ways to assist people who need medical care. Your participation in this interview is completely voluntary. If you don't want to participate, just let me know. Your decision won't change any services you receive as a client of the Department of Social and Health Services.

The questions I would ask are about such things as your health, and your involvement with the King County Care Partners Program. You may skip any question you don't want to answer. The questions take about 10 minutes to answer. We'd also like to give you a \$20 Safeway gift card for gas or food just to say, thank you, for doing the survey with us.

Your answers will be kept strictly confidential. If you decide to take part, your answers will be combined with answers from other people in the study. You won't be identified in any way.

This study may not help you directly, but your answers combined with those of others can help DSHS find ways to improve health care for people on Medicaid.

3. This interview is voluntary. If you don't want to participate, you don't have to. Also, if I ask anything you don't want to answer or that makes you feel uncomfortable, just let me know and I'll skip over it. Okay?

4. Is this a good time to complete the survey?

- o Yes → CONTINUE
- o No → IF NOT A CONVENIENT TIME, ARRANGE A TIME TO CALL FOR INTERVIEW
- o Client refuses to participate in survey

Date/Time for Interview: _____

B. CHAMMP Questions

5. Have you heard about the King County Care Partners Program?

- ☐ Yes → SKIP TO 7
- ☐ No → CONTINUE

Description: King County Care Partners – It's the program that helps you get extra help and services to get your health care needs met. A nurse or social worker from King County Care Partners meets with you, helps you figure out your health goals, and then works with you and your health care providers to reach those goals.

6. You have new benefits under Medicaid. Would you like to hear about them?

- ☐ Yes → GO TO HARD COPY Original KCCP Engagingg Script, THEN SKIP TO 35
- ☐ No → SKIP TO 35

7. When you spoke to the person who called to tell you about the King County Care Partners Program, did you AGREE to talk to a nurse or social worker from the program?

- ☐ Yes → CONTINUE
- ☐ No → SKIP TO 26

Question Set I

8. I'm going to read some reasons you may have agreed to speak to a nurse or social worker from the King County Care Partners Program. Please say YES to any of the following that were reasons you agreed to speak to them.

- a. I needed help in getting my health care needs met
- b. I wanted the \$10 Safeway certificate
- c. The person who called to tell me about the program was pleasant and friendly
- d. The person who called to tell me about the program convinced me it would be a good thing to do

9. In your own words, are there any other reasons that you agreed to talk to a nurse or social worker from the King County Care Partners Program ?

10. After you AGREED to talk to a nurse or social worker from King County Care Partners Program did you have AT LEAST ONE CONVERSATION with them?

- ☐ Yes → CONTINUE
- ☐ No → SKIP TO 35

Question Set 2

D. CSQ-8

Please help us improve our program by answering some questions about the services you have received. We are interested in your honest opinions, whether they are positive or negative. *Please answer all of the questions.*

10. How would you rate the quality of service you have received?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

11. Did you get the kind of service you wanted?

- ☐ No, definitely
- ☐ No, not really
- ☐ Yes, generally
- ☐ Yes, definitely

12. To what extent has our program met your needs?

- ☐ Almost all of my needs have been met
- ☐ Most of my needs have been met
- ☐ Only a few of my needs have been met
- ☐ None of my needs have been met

13. If a friend were in need of similar help, would you recommend our program to him or her?

- ☐ No, definitely not
- ☐ No, I don't think so
- ☐ Yes, I think so
- ☐ Yes, definitely

14. How satisfied were you with the amount of help you have received?

- ☐ Quite dissatisfied
- ☐ Indifferent or mildly dissatisfied
- ☐ Mostly satisfied
- ☐ Very satisfied

15. Have the services you received helped you deal more effectively with your problems?

- ☐ Yes, they helped a great deal
- ☐ Yes, they helped
- ☐ No, they really didn't help
- ☐ No, they seemed to make things worse

16. In an overall general sense, how satisfied are you with the service you received?

- ☐ Very satisfied
- ☐ Mostly satisfied
- ☐ Indifferent or mildly dissatisfied
- ☐ Quite dissatisfied

17. If you were to seek help again would you come back to our program?

- ☐ No, definitely not
- ☐ No, I don't think so
- ☐ Yes, I think so
- ☐ Yes, definitely

E. CHAMMP QUESTIONS

18. Did the program meet your expectations?

- ☐ Exceeded expectations
- ☐ Met many of my expectations
- ☐ Met a few expectations
- ☐ Did not meet my expectations

19. What did you like best about the King County Care Partners Program?

20. What did you like least about the King County Care Partners Program?

21. Did you and the nurse develop a set of healthcare goals that were important to you?

- ☐ Yes → CONTINUE
- ☐ No → SKIP TO 29

Question Set 3

22. I'm going to read some questions about your participation in the King County Care Partners Program. Please answer YES or NO.

a. Were you able to reach at least one of the healthcare goals you developed with your nurse?

- ☐ Yes
- ☐ No

b. Did the program help you feel you can take charge of your health?

- ☐ Yes
- ☐ No

c. Did the program help you get health care needs met that you could not have met on your own?

- ☐ Yes
- ☐ No

d. Did the program help you solve problems in your daily life, such as housing, transportation, or finances, that were stopping you from getting your health needs met?

- ☐ Yes
- ☐ No

f. Did the set of healthcare goals you developed with your nurse include your most important health care needs?

- ☐ Yes
- ☐ No

23. I'm going to read some questions about your nurse or social worker in the King County Care Partners Program. Please answer YES or NO.

a. Did you have a good, trusting relationship with the nurse or social worker?

- ☐ Yes
- ☐ No

b. In working with you, did your nurse or social worker push you too hard or hold you back?

- ☐ Yes
- ☐ No

c. Was it easy to reach the nurse or social worker?

- ☐ Yes
- ☐ No

d. Did your nurse teach you about your illness and ways to manage it?

- ☐ Yes
- ☐ No

e. Did your nurse or social worker understand your culture?

- ☐ Yes
- ☐ No

24. Are you still working with the nurse or social worker on your care needs?

- ☐ Yes → SKIP TO 35
- ☐ No → CONTINUE

25. Did you get their help as long as you wanted to?

- ☐ Yes → SKIP TO 35
- ☐ No → SKIP TO 32

Question Set 4

26. I'm going to read some reasons you may have DECIDED NOT TO TALK to a nurse or social worker from the King County Care Partners Program. Please say YES to any of the following that were reasons you decided not to talk to them.

- a. I had trouble getting in touch with them
- b. I didn't need the program; I was already happy with my health care
- c. I didn't want to answer lots of personal questions or have someone in my home.
- d. I was too busy or stressed

- e. I was in the hospital, in treatment, or too ill
- f. I was in jail

27. Were there problems that would make it hard for you to be in the program? Please answer YES to those that apply.

- a. Transportation problems
- b. Child care problems
- c. Homelessness or moving a lot
- d. No phone or limited access to a phone
- e. Problems because of a physical or mental disability, like deafness, immobility, or memory problems
- f. They didn't understand my language or culture

28. In your own words, are there any other reasons that you **DECIDED NOT TO TALK** to a nurse or social worker from the King County Care Program?

SKIP TO 35

Question Set 5

29. I'm going to read a list of reasons you may **NOT** have **FINISHED** developing a set of healthcare goals that are important to you with your nurse? Please say YES to the following that were reasons.

- a. My nurse and I are still working together on developing a set of healthcare goals that are important to me
- b. It was hard to schedule a time to meet with the nurse or social worker
- c. I became ineligible for the program
- d. I decided I wasn't interested in the program
- e. I didn't trust the nurse or social worker
- f. I was too busy or stressed
- g. I was in the hospital, in treatment, or too ill

- h. I was in jail

30. Were there problems that made it hard for you to finish developing a set of healthcare goals that are important to you with your nurse? Please answer YES to those that apply.

- a. Transportation problems
- b. Child care problems
- c. Homelessness or moving a lot
- d. No phone or limited access to a phone
- e. Problems because of a physical or mental disability, like deafness, immobility, or memory problems
- f. They didn't understand my language or culture

31. In your own words, are there other reasons that you DIDN'T FINISH developing a set of healthcare goals that are important to you with your nurse?

SKIP TO 35

Question Set 6

32. I'm going to read some reasons you did NOT GET HELP from the King County Care Program for AS LONG AS YOU WANTED. Please answer YES or NO.

- a. I became ineligible for the program
- b. I was unhappy with the program
- c. Nurse or social worker said I didn't need it anymore
- d. I was too busy or stressed
- e. I was in the hospital, in treatment, or too ill
- f. I was in jail

33. Were there problems that stopped you from getting help from the King County Care Program for as long as you wanted? Please answer YES to those that apply.

- a. Transportation problems
- b. Child care problems

- c. Homelessness or moving a lot
- d. No phone or limited access to a phone
- e. Problems because of a physical or mental disability, like deafness, immobility, or memory problems
- f. They didn't understand my language or culture

34. In your own words, are there any other reasons that stopped you from getting help from the King County Care Program for as long as you wanted?

Question Set 7

35. Would you say that in general your health is ...

Please read:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

Do not read:

- ☐ Don't know / Not sure
- ☐ Refused

F. EQ-5D

Please indicate which statements best describe your own health state TODAY.

36. Which statement best describes your **mobility**?

- ☐ I have no problems in walking about
- ☐ I have some problems in walking about
- ☐ I am confined to bed

37. Which statement best describes your **self-care**?

- ☐ I have no problems with self-care
- ☐ I have some problems washing or dressing myself
- ☐ I am unable to wash or dress myself

38. Which statement best describes your **usual activities** (e.g. work, study, housework, family, or leisure activities)?

- ☐ I have no problems with performing my usual activities
- ☐ I have some problems with performing my usual activities
- ☐ I am unable to perform my usual activities

39. Which statement best describes your **pain or discomfort**?

- ☐ I have no pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have extreme pain or discomfort

40. Which statement best describes your **anxiety or depression**?

- ☐ I am not anxious or depressed
- ☐ I am moderately anxious or depressed
- ☐ I am extremely anxious or depressed

41. A personal doctor is one you would see if you need a check-up, want advice about a health problem, or get sick or hurt. Do you have a personal doctor?

- ☐ Yes
- ☐ No

42. In the last six months, **not** counting the times you needed care right away, how often did you get an appointment for your healthcare at a doctor's office or clinic as soon as you thought you needed?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

G. Close

43. Is there anything else you would like to say about the King County Care Partners Program?

I'd like to check your address to make sure we send your gift card to the right place. We currently have your address as _____. Is that correct? (Make corrections on first page.)

Thank you for agreeing to be part of the study. Your participation is really appreciated and may help DSHS find out what types of programs work the best for its clients on Medicaid.

Appendix D. Summary of Survey Responses (frequencies)

Demographics (all groups, n = 286)

Group

Group	Description	Question Sets	N	%
A	Completed care plan, still participating or participated as long as they wanted	Demographics, 1, 2, 3, 7	105	37
B	Completed care plan, didn't participate in program as long as they wanted	Demographics, 1, 2, 3, 6, 7	16	6
C	Agreed to participate, didn't complete care plan	Demographics, 1, 2, 5, 7	33	12
D	Didn't agree to participate ²³	Demographics, 4, 7	36	13
E	Never heard about the program	Demographics, 7	96	34
		Survey Total	286	100
F	Not interviewed	Demographics	120	

Gender

Survey sample

	n	%
Female	164	57
Male	122	43
Total	286	100

Age

Survey sample

	n	%
50-59	119	42
40-49	82	29
20-39	44	15
60-85	41	14
Total	286	100

Race

Survey sample

	n	%
White	159	56
Black	77	27
Other	50	17
Total	286	100

²³ Fifteen of the thirty-six individuals in Group D initially agreed to talk to a nurse or social worker from KCCP, but never had a conversation with them.

Mental Illness

Survey sample

	n	%
High	138	48
Low	134	47
None	14	5
Total	286	100

Needs Treatment

Survey sample

	n	%
No	153	53
Yes	133	47
Total	286	100

Co-occurring Treatment Need and Mental Illness

Survey sample

	n	%
No	163	57
Yes	123	43
Total	286	100

Co-occurring Treatment Need and Mental Illness - high

Survey sample

	n	%
No	209	73
Yes	77	27
Total	286	100

Co-occurring Treatment Need and Mental Illness – low

Survey sample

	n	%
No	240	84
Yes	46	16
Total	286	100

Risk score

Survey sample

	n	%
1.5 - 1.99999	129	45
2.0 - 2.4999999	83	29
2.5 and over	74	26
Total	286	100

Survey completion code

	n	%
Completed	286	70
Physically or cognitively unable to respond and no other respondent available; or interview completed by a collateral	29	7
Deceased	27	7
No answer - phone temporarily out of service - not accepting calls - VM not set up	20	5
Refused	16	4
Can't find	12	3
Homeless and can't reach	6	1
Jail or prison	3	1
We have a correct address but phone is not listed anywhere - may not have one.	2	0
No phone - we have a correct address, but client has no phone	2	0
Nursing home - not able to speak to client	1	0
Out of country	1	0
Hospice	1	0
Total	406	100

Question Set I (Groups A, B, C, D)

5. Have you heard about the King County Care Partners Program? *(If yes, skip to 7)*

	n	%
Yes	190	66
No	96	34
Total	286	100

6. You have new benefits under Medicaid. Would you like to hear about them? *(If no, skip to 35)*

	n	%
Yes	68	71
No	28	29
Total	96	100

7. When you spoke to the person who called to tell you about the King County Care Partners Program, did you AGREE to talk to a nurse or social worker from the program? *(If no, skip to 26)*

	n	%
Yes	169	89
No	21	11
Total	190	100

8. I'm going to read some reasons you may have agreed to speak to a nurse or social worker from the King County Care Partners Program. Please say YES to any of the following that were reasons you agreed to speak to them.

	n	%
I needed help in getting my health care needs met	123	80
I wanted the \$10 Safeway certificate	89	58
The person who called to tell me about the program was pleasant and friendly	139	90
The person who called to tell me about the program convinced me it would be a good thing to do	122	79

10. After you AGREED to talk to a nurse or social worker from King County Care Partners Program did you have AT LEAST ONE CONVERSATION with them? *(If no, skip to 35)*

	n	%
No	15	9
Yes	154	91
Total	169	100

Question Set 2 *(Groups A, B, C)*

CSQ-8

- 10b. How would you rate the quality of service you have received?

	n	%
Excellent	89	59
Good	40	27
Fair	15	10
Poor	6	4
Total	150	100
Missing	4	
	154	

11. Did you get the kind of service you wanted?

	n	%
Yes, definitely	81	54
Yes, generally	50	34
No, not really	12	8
No, definitely	6	4
Total	149	100
Missing	5	
	154	

12. To what extent has our program met your needs?

	n	%
Almost all of my needs have been met	62	41
Most of my needs have been met	42	28
Only a few of my needs have been met	29	19
None of my needs have been met	17	11
Total	150	100
Missing	4	
	154	

13. If a friend were in need of similar help, would you recommend our program to him or her?

	n	%
Yes, definitely	111	74
Yes, I think so	31	21
No, I don't think so	5	3
No, definitely not	3	2
Total	150	100
Missing	4	
	154	

14. How satisfied were you with the amount of help you have received?

	n	%
Very satisfied	87	60
Mostly satisfied	39	27
Indifferent or mostly dissatisfied	11	8
Quite dissatisfied	9	6
Total	146	100
Missing	8	
	154	

15. Have the services you received helped you deal more effectively with your problems?

	n	%
Yes, they helped a great deal	68	46
Yes, they helped	54	37
No, they really didn't help	22	15
No, they seemed to make things worse	3	2
Total	147	100
Missing	7	
	154	

16. In an overall general sense, how satisfied are you with the service you received?

	n	%
Very satisfied	85	57
Mostly satisfied	43	29
Indifferent or mildly satisfied	14	9
Quite dissatisfied	8	5
Total	150	100
Missing	4	
	154	

17. If you were to seek help again would you come back to our program?

	n	%
Yes, definitely	110	73
Yes, I think so	30	20
No, definitely not	6	4
No, I don't think so	4	3
Total	150	100
Missing	4	
	154	

CHAMMP Questions

18. Did the program meet your expectations?

	n	%
Met many of my expectations	56	38
Exceeded expectations	40	27
Met a few expectations	35	23
Did not meet my expectations	18	12
Total	149	100
Missing	5	
	154	

21. Did you and the nurse develop a set of healthcare goals that were important to you? (If no, skip to 29)

	n	%
Yes	121	79
No	33	21
Total	154	100

Question Set 3 (Groups A, B)

22. I'm going to read some questions about your participation in the King County Care Partners Program. Please answer YES or NO.

a. Were you able to reach at least one of the healthcare goals you developed with your nurse?

	n	%
Yes	106	90
No	12	10
Total	118	100
Missing	3	
	121	

b. Did the program help you feel you can take charge of your health?

	n	%
Yes	108	91
No	11	9
Total	119	100
Missing	2	
	121	

c. Did the program help you get health care needs met that you could not have met on your own?

	n	%
Yes	98	82
No	21	18
Total	119	100
Missing	2	
	121	

d. Did the program help you solve problems in your daily life, such as housing, transportation, or finances, that were stopping you from getting your health needs met?

	n	%
Yes	78	65
No	42	35
Total	120	100
99	1	
	121	

- e. Did the set of healthcare goals you developed with your nurse include your most important health care needs?

	n	%
Yes	109	92
No	9	8
Total	118	100
99	3	
	121	

23. I'm going to read some questions about your nurse or social worker in the King County Care Partners Program. Please answer YES or NO.

- a. Did you have a good, trusting relationship with the nurse or social worker?

	n	%
Yes	118	98
No	3	2
Total	121	100

- b. In working with you, did your nurse or social worker push you too hard or hold you back?

	n	%
No	109	90
Yes	12	10
Total	121	100

- c. Was it easy to reach the nurse or social worker?

	n	%
Yes	111	93
No	8	7
Total	119	100
Missing	2	
	121	

- d. Did your nurse teach you about your illness and ways to manage it?

	n	%
Yes	103	87
No	16	13
Total	119	100
Missing	2	
	121	

e. Did your nurse or social worker understand your culture?

	n	%
Yes	105	91
No	11	9
Total	116	100
Missing	5	
	121	

24. Are you still working with the nurse or social worker on your care needs? (If yes, skip to 35)

	n	%
Yes	82	68
No	39	32
Total	121	100

25. Did you get their help as long as you wanted to? (If yes, skip to 35; If no, skip to 32)

	n	%
Yes	23	59
No	16	41
Total	39	100
Missing	82	
	121	

Question Set 4 (Group D, n = 36)

26. I'm going to read some reasons you may have DECIDED NOT TO TALK to a nurse or social worker from the King County Care Partners Program. Please say YES to any of the following that were reasons you decided not to talk to them.

	n	%
I had trouble getting in touch with each them	2	6
I didn't need the program; I was already happy with my health care	10	28
I didn't want to answer lots of personal questions or have someone in my home.	4	11
I was too busy or stressed	4	11
I was in the hospital, in treatment, or too ill	3	8
I was in jail	0	0

27. Were there problems that would make it hard for you to be in the program? Please answer YES to those that apply.

	n	%
Transportation problems	2	6
Child care problems	0	0
Homelessness or moving a lot	1	3
No phone or limited access to a phone	0	0
Problems because of a physical or mental disability, like deafness, immobility, or memory problems	3	8
They didn't understand my language or culture	2	6

Question Set 5 (Group C, n = 33)

29. I'm going to read a list of reasons you may NOT have FINISHED developing a set of healthcare goals that are important to you with your nurse? Please say YES to the following that were reasons.

	n	%
My nurse and I are still working together on developing a set of healthcare goals that are important to me	9	27
It was hard to schedule a time to meet with the nurse or social worker	10	30
I became ineligible for the program	2	6
I decided I wasn't interested in the program	7	21
I didn't trust the nurse or social worker	4	12
I was too busy or stressed	7	21
I was in the hospital, in treatment, or too ill	3	9
I was in jail	0	0

30. Were there problems that made it hard for you to finish developing a set of healthcare goals that are important to you with your nurse? Please answer YES to those that apply.

	n	%
Transportation problems	3	9
Child care problems	0	0
Homelessness or moving a lot	6	18
No phone or limited access to a phone	2	6
Problems because of a physical or mental disability, like deafness, immobility, or memory problems	3	9
They didn't understand my language or culture	0	0

Question Set 6 (Group B, n = 16)

32. I'm going to read some reasons you did NOT GET HELP from the King County Care Program for AS LONG AS YOU WANTED. Please answer YES or NO.

	n	%
I became ineligible for the program	2	13
I was unhappy with the program	1	6
Nurse or social worker said I didn't need it anymore	1	6
I was too busy or stressed	2	13
I was in the hospital, in treatment, or too ill	2	13
I was in jail	0	0

33. Were there problems that stopped you from getting help from the King County Care Program for as long as you wanted? Please answer YES to those that apply.

	n	%
Transportation problems	0	0
Child care problems	0	0
Homelessness or moving a lot	0	0
No phone or limited access to a phone	1	6
Problems because of a physical or mental disability, like deafness, immobility, or memory problems	1	6
They didn't understand my language or culture	0	0

Question Set 7 (all groups, n = 286)

35. Would you say that in general your health is ...

	n	%
Excellent	5	2
Very good	16	6
Good	64	22
Fair	99	35
Poor	99	35
Don't know / Not sure	2	1
Total	285	100
Missing	1	
	286	

EQ-5D

Please indicate which statements best describe your own health state TODAY.

36. Which statement best describes your **mobility**?

	n	%
I have no problems walking about	58	20
I have some problems walking about	208	73
I am confined to bed	17	6
Total	283	100
Missing	3	
	286	

37. Which statement best describes your **self-care**?

	n	%
I have no problems with self-care	151	53
I have some problems washing or dressing myself	108	38
I am unable to wash or dress myself	25	9
Total	284	100
Missing	2	
	286	

38. Which statement best describes your **usual activities** (e.g. work, study, housework, family, or leisure activities)?

	n	%
I have no problems with performing my usual activities	60	21
I have some problems with performing my usual activities	164	58
I am unable to perform my usual activities	59	21
Total	283	100
Missing	3	
	286	

39. Which statement best describes your **pain or discomfort**?

	n	%
I have no pain or discomfort	37	13
I have moderate pain or discomfort	136	48
I have extreme pain or discomfort	110	39
Total	283	100
Missing	3	
	286	

40. Which statement best describes your **anxiety or depression**?

	n	%
I am not anxious or depressed	70	25
I am moderately anxious or depressed	132	47
I am extremely anxious or depressed	81	29
Total	283	100
Missing	3	
	286	

41. A personal doctor is one you would see if you need a check-up, want advice about a health problem, or get sick or hurt. Do you have a personal doctor?

	n	%
No	20	7
Yes	265	93
Total	285	100
Missing	1	
	286	

42. In the last six months, **not** counting the times you needed care right away, how often did you get an appointment for your healthcare at a doctor's office or clinic as soon as you thought you needed?

	n	%
Never	9	3
Sometimes	55	20
Usually	60	22
Always	150	55
Total	274	100
Missing	12	
	286	

Interviewer: How would you rate the **QUALITY** of information obtained in this interview?

	n	%
Excellent, no problems at all	223	78
Good, a few problems but overall quality is good	52	18
Fair, a number of problems but overall acceptable	11	4
Total	286	100

Appendix E1. Open-Ended Responses: Reasons Clients Agreed to Talk to KCCP Staff

Question

In your own words, are there any other reasons that you agreed to talk to a nurse or social worker from the King County Care Partners Program?

Legend

Group	Description	Total no. of clients asked this question	Total no. and % of clients who responded to this question	Total no. of response codes
A	Completed care plan, still participating or participated as long as they wanted	105	63 (60%)	70
B	Completed care plan, didn't participate in program as long as they wanted	16	9 (56%)	10
C	Agreed to participate, didn't complete care plan	33	23 (70%)	26
	Total	154	95 (62%)	106

Coding Summary across Groups

Code	Major themes	Group A n ²⁴ = 63 n ²⁵ %		Group B n = 9 n %		Group C n = 23 n %		Overall n = 95 n %	
1	I needed help with my medical problems.	18	29	4	44	7	30	29	31
2	I needed help.	14	22	2	22	3	13	19	20
3	I wanted help with housing.	6	10	0	0	6	26	12	13
4	I wanted more information on my medical problems.	6	10	1	11	1	4	8	8
5	I wanted somebody to go to my medical appointments with me or I needed help making appointments.	7	11	0	0	1	4	8	8
6	I was interested in or curious about their services.	4	6	1	11	0	0	5	5
7	I needed help with my medications.	2	3	1	11	1	4	4	4
8	I needed help with my mental health or substance abuse problems.	5	8	0	0	0	0	5	5
9	I needed help finding a doctor.	3	5	0	0	1	4	4	4
10	I wanted somebody to talk to.	0	0	0	0	2	9	2	2
11	They told me about dental programs.	1	2	0	0	1	4	2	2
12	My doctor or DSHS thought it would be a good thing for me to do.	1	2	0	0	1	4	2	2
13	Other	3	5	1	11	2	9	6	6

²⁴ n represents the number of people in that group who provided a response to this open-ended question.

²⁵ n represents the number of clients whose comment was coded under that theme. For example, 18 clients in Group A made comments suggesting that they needed help with their medical problems.

Responses and Coding (n=103)

Group	Are there any other reasons that you agreed to talk to a nurse or social worker from the King County Care Partners Program?	Code 1	Code 2
A	He was in need of additional medical care. I needed help in finding housing.	1	3
A	I believed the program was a good program and I REALLY needed help with my health care needs. I also need help with my housing, as my apartment flooded.	1	3
A	I need some additional information and help with my medical care.	1	4
A	Because she is helping me with my health needs and checking on my mental needs.	1	8
A	She agreed to help me with my medical problems.	1	
A	Because I have had multiple medical post-operative complications from open heart surgery.	1	
A	Because I thought maybe this would be helpful with my diabetes	1	
A	Because of my health.	1	
A	Health issues that I wanted help with.	1	
A	I did not get a \$10 Safeway Certificate. She agreed to help me with my medical problems.	1	
A	I needed help getting better care.	1	
A	I wanted help with my health needs - I needed help with my COPD, diabetes and high blood pressure.	1	
A	Just to advance my healthcare.	1	
A	No, just about health issues.	1	
A	She advised me that she could help me with my medical problems.	1	
A	She offered me resources and networking to help me with my medical needs.	1	
A	The nurse stated that she would be able to help me with my medical needs.	1	
A	Well, in 2006 I suffered a very serious illness which left me disabled with several chronic conditions. I believe that the more contact I have with healthcare providers - the better off I am.	1	
A	Felt like it would give me something to fall back on, if the program I'm on fell through.	2	
A	For personal assistance.	2	
A	I felt that they could help me.	2	
A	I needed the HELP.	2	
A	It just seemed like a good program in theory and that I needed that at the time.	2	
A	It sounded nice to have somebody for extra support.	2	
A	Just to get all the help possible.	2	
A	No, I need someone to help me.	2	
A	They helped me get things done that I couldn't get done by myself.	2	
A	They maybe could help me with me problems.	2	
A	To get help with everything that I need.	2	
A	Yes, because she said she could help with extra things that could be done.	2	
A	Yes, she needed help after her stroke and also to be able to keep up with her daily household chores.	2	
A	You had a lot of problems and you were hoping that KCCP program could help you.	2	
A	At the time, I had been homeless for a while - I thought I needed the extra help with Sec. 8 and other needs.	3	
A	I needed help in getting housing.	3	
A	I needed to have some help with my living situation.	3	
A	She also stated that she could help me find housing.	3	
A	Yes. I have some other health issues and the person that works with me and the home nurse got me information on my illness and got information on the stop smoking program and referral for a different dentist in the area.	4	11

Group	Are there any other reasons that you agreed to talk to a nurse or social worker from the King County Care Partners Program?	Code 1	Code 2
A	Because they were helpful to find information that I was unable to find.	4	
A	I thought it would be good for me since I am at home and I might have questions to ask the nurse.	4	
A	I thought that I could get information that would help me in my current situation.	4	
A	I was interested in finding out about additional medical information.	4	
A	I needed to have someone help me with my prescriptions and my doctors appointments and make for sure that I went to the right place on the right day and that I took the right medicine and the nurse assured me that she could help.	5	7
A	I was going through depression because of my health and they were able to help me with that in getting some of my needs met. KCCP alerted my doctor as to my needs.	5	8
A	I asked her if she would go to the doctor with me.	5	
A	In the past, I had some problems with my doctors and misunderstandings - it would have been good to have the nurse available at that time.	5	
A	It's always good to have an advocate when working with the medical services.	5	
A	They helped me along with my medical doctor to get answers that weren't being given to me.	5	
A	I thought that it would benefit me in helping me get to my doctors appointments.	5	
A	Curiosity	6	
A	Curiosity	6	
A	Just to make some connections and see what it was about. I did not get a \$10.00 Safeway Certificate.	6	
A	I am concerned about my health and it was a good opportunity to take advantage of services that I did not have.	6	
A	I thought that it would be a good idea to have someone follow the medicine that my mother was taking. I did not get a \$10 Safeway Certificate.	7	
A	I just needed help because of my depression.	8	
A	Yes, because they helped me get into Seattle Mental Health program.	8	
A	Because I needed to get into an alcohol and drug program.	8	
A	I talked to her because I was always in the Emergency Room and never got to see my primary provider.	9	
A	The main reason is that she told me that she could help me get another primary care provider because I had just ended my relationship with my doctor and I needed to find another one.	9	
A	They told me that there was a clinic down the street Neighbor Care that they would help me get into to see a doctor for my medical needs.	9	
A	Just because DSHS thought KCCP could help me more than what I was getting from DSHS.	12	
A	Very friendly.	13	
A	I think due to the fact they are affiliated with Aging Services, that they would be good to deal with.	13	
A	I thought it was mandatory that I get the service.	13	
B	Yes, I thought they might help with meds and possible new treatment for my disease.	1	7
B	No other reasons. I only wanted help getting some surgery.	1	
B	Originally, I was very ill and any help I could [get] was good.	1	
B	To get additional medical help. I did not get the \$10 Safeway Gift Card.	1	
B	I just felt that I needed extra support and it sounded like a good idea.	2	
B	They agreed to help me with getting assistance from the state.	2	
B	To try and find information about your medical problems.	4	
B	I wanted to check out the program and see what they had to offer.	6	
B	Yes. She had some resources that I thought would be good to have.	13	

Group	Are there any other reasons that you agreed to talk to a nurse or social worker from the King County Care Partners Program?	Code 1	Code 2
C	They said they could help me with my chronic health issues and housing, etc.	1	3
C	I want some help to get my health under control and my doctors and finding the right doctor.	1	9
C	I didn't feel like I was getting my needs completely met through Community Health. They just herd you in and herd you out.	1	
C	I had some fears about life expectancy and I was looking for help.	1	
C	I was having health issues at the time and needed some help.	1	
C	It was an advantage to me and they explained that they could help me with my health care needs.	1	
C	To get additional medical help.	1	
C	I never received the \$10 Safeway gift card. I had problems and I hope that they could help me with them.	2	
C	Wanted to make sure if there was anything in the program that would help.	2	
C	Yes, they told me that they could help me with anything I needed.	2	
C	At the time I was contacted I needed housing and it was possible for me to get housing. I might be able to get housing, but that was untrue.	3	
C	I thought that the nurse would be able to help me get into a larger house than I was able to get.	3	
C	I was homeless and I needed a place to stay that was safe.	3	
C	KCCP agreed to help me get housing.	3	
C	Because I needed a chair to sit outside.	3	
C	I wanted to learn more facts about physical health.	4	
C	I was having trouble getting my doctors appointment and getting her to refill my prescriptions.	5	7
C	I just like to talk to people - I don't get out very much.	10	
C	I needed someone to come and talk to me.	10	
C	I called the KCCP Program and they advised me of some dental programs available.	11	
C	My doctor thought it would be a beneficial thing to do.	12	
C	Only because I was a part of Medicaid already	13	
C	Only because they kept calling me.	13	

Appendix E2. Open-Ended Responses: Reasons for Ending Participation Early

Question

In your own words, are there any other reasons that stopped you from getting help from the King County Care Program for as long as you wanted?

Legend

Group	Description	Total no. of clients asked this question	Total no. and % of clients who responded to this question	Total no. of response codes
B	Completed care plan, didn't participate in program as long as they wanted	16	12 (75%)	12

Coding Summary

Code	Major themes	Group B n ²⁶ = 12 n ²⁷ %
1	My first nurse left and my replacement nurse never followed up.	8 67
2	Somebody called/told me that my time allotment was finished.	2 17
3	I wanted more help.	1 8
4	I didn't need it.	1 8

Responses and Coding (n=12)

Group	In your own words, are there any other reasons that stopped you from getting help from the King County Care Program for as long as you wanted?	Code 1
B	I had a nurse named [redacted] who was coming each month and taking care of me. She retired and I got a call from her replacement who was to meet me at my doctors appointment, but never showed up and I have never heard from her since.	1
B	I stopped because the follow-up nurse did not contact me after the first nurse left. I'm still interested in the program. Please have someone call me. My gift card did not work!	1
B	Lack of personnel who would follow through with what was started from another worker that quit.	1
B	My nurse quit and they never gave me a replacement nurse and the case just stopped being worked on and they finally just closed it down. They did call me to ask my permission to close it and I agreed.	1
B	The nurse left and it was too late to get another one.	1
B	The nurse stopped coming and I was told she got fired.	1
B	The nurse that I had named [redacted] quit and I have never seen another one, but I would like to.	1
B	The nurse was let go by KCCP and I haven't had a new nurse assigned yet.	1
B	She called and said that it would be ending for me.	2
B	The nurse stated that my time allotment was finished and they would be sending me a referral to continue the program at my regular care providers office.	2
B	No, I wanted more help.	3
B	I did not feel that I needed it. I have been doing this for years on my own.	4

²⁶ n represents the number of people in that group who provided a response to this open-ended question.

²⁷ n represents the number of clients whose comment was coded under that theme. For example, 8 clients in Group B made comments suggesting that their first nurse left and a replacement nurse never followed up.

Appendix E3. Open-Ended Responses: Reasons for not Developing Healthcare Goals

Question

In your own words, are there other reasons that you DIDN'T FINISH developing a set of healthcare goals that are important to you with your nurse?

Legend

Group	Description	Total no. of clients asked this question	Total no. and % of clients who responded to this question	Total no. of response codes
C	Agreed to participate, didn't complete care plan	33	22 (67%)	22

Coding Summary

Code	Major themes	Group C n ²⁸ = 22 n ²⁹ %	
1	The nurse did not follow up with me.	6	27
2	Life stressors got in the way.	5	23
3	I didn't need the program.	4	18
4	I don't know or remember if we set up any goals.	4	18
5	I was unable to because of eligibility issues.	2	9
6	They stated that the program was not helping either party.	1	5

Responses and Coding (n=22)

Group	In your own words, are there other reasons that you DIDN'T FINISH developing a set of healthcare goals that are important to you with your nurse?	Code 1
C	The nurse never contacted me and I just wanted a referral to the dentist.	1
C	The nurse didn't follow through with me.	1
C	The nurse didn't do the follow through like I had hoped. Lots of phone tag and didn't get to talk with her.	1
C	The nurse and I did not get around to making or developing a set of healthcare goals.	1
C	I have not heard from the nurse in months and I do not know if I am still on the program.	1
C	She gave me the wrong impression when she came to see me and we never completed the goals.	1
C	My son got into trouble that was very stressful and depressing to me and it has been hard to meet with the nurse.	2
C	Because of a death in the family, I have been unable to get together with the nurse.	2
C	Too many issues to deal with.	2
C	Medical issues and not being able to get around. Also have mental issues.	2
C	I was homeless and unable to get together with the nurse or social worker.	2
C	They didn't have the services I was looking for and my mother does the things that the program would be able to provide.	3
C	I didn't need help at the time, but I could use some now.	3

²⁸ n represents the number of people in that group who provided a response to this open-ended question.

²⁹ n represents the number of clients whose comment was coded under that theme. For example, 6 clients in Group C made comments suggesting the nurse did not follow up with them.

Group	In your own words, are there other reasons that you DIDN'T FINISH developing a set of healthcare goals that are important to you with your nurse?	Code I
C	Don't have anything for me. They just want me to go to the nursing home. I'm not going to do that!	3
C	Because all my current healthcare needs are met.	3
C	I don't remember what services that they have provided for me.	4
C	I don't remember if I set up any healthcare goals with my nurse.	4
C	I don't know if she had set up any healthcare goal for me. She only left me with informational papers and nothing to do with what I needed to do to improve my health.	4
C	I already had my healthcare goals set, but [the] nurse didn't explain what [was] available.	4
C	Nope, I was cut off because I got a job.	5
C	Because of the medical coupons and I was trying to get that straighten out.	5
C	They stated that the program was not helping either party.	6

Appendix E4. Open-Ended Responses: Reasons for not Talking to KCCP

Question

In your own words, are there any other reasons that you DECIDED NOT TO TALK to a nurse or social worker from the King County Care Program?

Legend

Group	Description	Total no. of clients asked this question	Total no. and % of clients who responded to this question	Total no. of response codes
D	Didn't agree to participate	36	10 (28%)	10

Coding Summary

Code	Major themes	Group D n ³⁰ = 10 n ³¹	%
1	I didn't need the program.	3	30
2	I wasn't eligible for the program.	3	30
3	My family doesn't want me to be in the program.	1	10
4	For some reason, I just didn't return their phone calls or letters.	1	10
5	They weren't able to help get us a hospital bed.	1	10
6	I haven't talked with anyone.	1	10

Responses and Coding (n=10)

Group	In your own words, are there any other reasons that you DECIDED NOT TO TALK to a nurse or social worker from the King County Care Program?	Code I
D	I didn't need their services.	1
D	I have a case manager who comes to see me every week from Evergreen Healthcare, so I don't believe I need the extra service.	1
D	I have a lot appointments and have everything down to a schedule, so I didn't need them	1
D	He lived in Pierce County and was not eligible.	2
D	I received about 5 phone calls and it was determined that [redacted] was not eligible for the services.	2
D	N/A, not eligible as lives in an assisted living facility	2
D	My family didn't want me to become involved with KCCP.	3
D	Very slow getting back to phone call left. For some reason, just did not return the calls or letters.	4
D	They weren't able to help get us get a hospital bed. The DSHS case manager helped get the bed.	5
D	I haven't talked with anyone.	6

³⁰ n represents the number of people in that group who provided a response to this open-ended question.

³¹ n represents the number of clients whose comment was coded under that theme. For example, 3 clients in Group D made comments suggesting that they didn't need the program.

Appendix E5. Open-Ended Responses: What Clients Liked Best About KCCP

Question

What did you like best about the King County Care Partners Program?

Legend

Group	Description	Total no. of clients asked this question	Total no. and % of clients who responded to this question	Total no. of response codes
A	Completed care plan, still participating or participated as long as they wanted	105	101 (96%)	155
B	Completed care plan, didn't participate in program as long as they wanted	16	14 (88%)	17
C	Agreed to participate, didn't complete care plan	33	21 (64%)	25
	Total	154	136 (88%)	197

Coding Summary across Groups

Code	Major themes	Group A n ³² = 101 n ³³ %		Group B n = 14 n %		Group C n = 21 n %		Overall n = 136 n %	
	Staff								
1	The staff were friendly/helpful.	31	31	9	64	7	33	47	35
2	The staff were genuinely concerned about me.	14	14	1	7	1	5	16	12
3	The staff were professional: went above and beyond, involved, or knowledgeable.	8	8	2	14	0	0	10	7
	Activities								
4	The staff or program helped with my healthcare and/or medical problems.	21	21	0	0	0	0	21	15
5	The staff helped with housing and transportation.	10	10	0	0	0	0	10	7
6	The staff acted as a liaison with providers at my medical appointments.	8	8	0	0	1	5	9	7
7	The staff/program followed up with my care.	7	7	0	0	1	5	8	6
8	I liked the home visits/face-to-face meetings.	8	8	0	0	0	0	8	6
9	I liked the referrals and/or resources.	4	4	0	0	0	0	4	3
10	I liked the case management.	1	1	0	0	0	0	1	1
11	They taught me how to advocate for my self.	1	1	0	0	0	0	1	1
12	I liked the initial introduction to the program.	1	1	0	0	0	0	1	1
	Program								
13	I liked everything; or the program was generally helpful.	13	13	0	0	0	0	13	10
14	I liked the support it gave me - the staff were easy to contact and they listened.	7	7	1	7	1	5	9	7
15	I liked the services and/or special programs.	2	2	1	7	0	0	3	2
16	I like that the program was one-on-one and individualized.	3	3	0	0	0	0	3	2
17	It was convenient and/or efficient.	1	1	0	0	1	5	2	0
	Information								
18	I liked the information I received.	6	6	2	14	3	14	11	8

³² n represents the number of people in that group who provided a response to this open-ended question.

³³ n represents the number of clients whose comment was coded under that theme. For example, 31 clients in Group A made comments suggesting that the staff were friendly/helpful.

Code	Major themes	Group A n ³⁴ = 101 n ³⁵ %		Group B n = 14 n %		Group C n = 21 n %		Overall n = 136 n %	
19	I liked the answers and explanations I got for my questions.	4	4	0	0	3	14	7	5
20	They gave me information on my rights.	2	2	0	0	0	0	2	1
	Miscellaneous								
21	I didn't like anything.	1	1	1	7	4	19	6	4
22	I don't know or I can't answer that question.	0	0	0	0	2	10	2	1
23	It was just okay.	1	1	0	0	0	0	1	1
	Feelings								
24	They gave me hope about my medical issues.	0	0	0	0	1	5	1	1
25	I feel more confident now.	1	1	0	0	0	0	1	1

Responses and Coding (n = 136)

Group	What did you like best about the King County Care Partners Program?	Code 1	Code 2	Code 3	Code 4
A	About how personal the nurse and social worker were and how nice they were to me. They were interested in my well being.	1	2		
A	I liked that they were very friendly, and non-judgmental and they were very helpful when I presented my problems.	1	2		
A	The nurse is very concerned and nice.	1	2		
A	The way the nurse talked to me after I met her and when she talked to me on the phone. She is very understanding.	1	2		
A	Their follow-up, friendliness and concern. They knew about my case and did not call up blind.	1	2	3	7
A	They were very easy to talk to and very understanding.	1	2		
A	I think I like the compassion they show and their willingness to help you with any problems.	1	2		
A	The willingness to care and offer help in any way that was needed.	1	2		
A	They are open-hearted to people. They really helped me.	1	2		
A	I think the kindness of the social worker, and her interest in me. She went out of her way to bring some books to read.	1	3		
A	I like the professionalism of the nurse. I like the personality of the nurse. I like the knowledge of the nurse.	1	3		
A	I think that they are very involved and they have really helped us when we have gone to doctor.	1	3		
A	The nurse was very nice and she helped me with my medical problems.	1	4		
A	The service door to door provided by [redacted]. She was great! All staff are great!	1	8		

³⁴ n represents the number of people in that group who provided a response to this open-ended question.

³⁵ n represents the number of clients whose comment was coded under that theme. For example, 31 clients in Group A made comments suggesting that the staff were friendly/helpful.

Group	What did you like best about the King County Care Partners Program?	Code 1	Code 2	Code 3	Code 4
A	Just the fact that people took time to hear and address my needs. I wasn't just a name on piece of paper - they actually tried to help me.	1	13		
A	The nurse that comes out to see me - we met and it was like we already knew each other. The program has been excellent for me.	1	13		
A	The program was very informative and the services were great. They were there to help me when I needed it.	1	15	18	
A	The fact that they take the time to help you and find out information that you couldn't find to help.	1	18		
A	Friendly staff.	1			
A	I didn't see anything negative about the services. Always very helpful.	1			
A	I liked that she was a very nice woman. When we met, we went to an agreed upon location and she spent quality time with me - as much as I needed. She was great to talk to and understood my needs. I felt very comfortable around her. Her name was [redacted].	1			
A	I liked that the person that I dealt with was easy to talk to and was very friendly [redacted].	1			
A	I liked that they came to help and located the help I needed.	1			
A	I liked the person who was coming to see me. They help me with a lot of my problems	1			
A	My case manager, [redacted].	1			
A	Nurses are very nice and considerate.	1			
A	She was friendly.	1			
A	The nurse was very helpful and I am grateful that she was there.	1			
A	The nurse was very helpful.	1			
A	The people were nice.	1			
A	Very pleasant, wanted to be helpful.	1			
A	That the worker showed some genuine concern. She more or less made sure I made my appointments and met me at whatever I was supposed to.	2	4		
A	The nurse showed that she was very concerned about my health problems and help me with them.	2	4		
A	That I could talk openly to my nurse and case worker. It helped make them understand what I need help with. They helped me get an apartment.	2	5		
A	The fact that she was interested in what my problems were.	2			
A	They were very open with me.	2			
A	The involvement and willingness to help find services and to make it possible to live at home and to get the kind of care needed.	3	4	5	
A	How easy it was to contact staff and get my questions answered. They were very prompt with their call backs and responses.	3	14	19	

Group	What did you like best about the King County Care Partners Program?	Code 1	Code 2	Code 3	Code 4
A	The gals were great - they give you the information - they send it in the mail. They call you back promptly. They did a wonderful job.	3	18		
A	I like it because they tell me things that I might not like to hear but I need to hear.	3			
A	They have helped me with my wheelchair and my other medical problems, transportation to get to the doctor.	4	5		
A	Caseworker helped me with my housing application and helped me with my doctors appointments.	4	5		
A	[Redacted] sent me a bunch of applications for King County and Seattle housing. A case manager from Healthpoint is trying to get in touch with [redacted] so we can complete these applications. [Redacted] - she met me at the hospital and watched me during my physical therapy. She checked on my needs and goals.	4	5	7	
A	How much [redacted] helped with my appointments, she came to my appointments with me. She reminded me of things I needed to discuss with the doctor. She arranged for rides with HopeLink.	4	5	6	
A	She helped me with my medical problems. She went with me to my medical doctor to help me understand the medical problems that I was having.	4	6		
A	I like the one-on-one service I got, I liked that the nurse came to the house to talk with me and that she goes to my appointments with me.	4	8	16	
A	The nurse came to my house and spoke to me personally at home instead of over the phone and helped me with my medical needs.	4	8	16	
A	They came out to my house at the time that I had no doctor and couldn't get my medicine. Now I have both.	4	8		
A	They found places that I could go to, to get help that were close to me. They give me additional resources that I needed for my health care.	4	9		
A	That I had a nurse to talk to when I needed help with my health.	4	14		
A	Just gave me some helpful information and I now have doctors near where I live.	4	18		
A	It helped me with my medicine and my doctor visits. My medicine is now given to me in bubble wrap and it makes it much easier to take.	4			
A	It helps me get to all of my doctors appointments.	4			
A	[Redacted], the nurse has been very helpful with medications and doctors appointments.	4			
A	The help with my doctors appointments.	4			
A	They helped me find a doctor for my health problems.	4			
A	They helped me with my medical needs after I was hospitalized.	4			
A	She has helped me get into housing that is affordable and get my life into the order that is good to live by. I am glad that she has helped so much.	5			
A	The nurse is helping me find a place to live.	5			

Group	What did you like best about the King County Care Partners Program?	Code 1	Code 2	Code 3	Code 4
A	The rides and transportation back and forth to the doctor for my foot surgery.	5			
A	They are trying to get me housing.	5			
A	They stay in touch with you and sometimes go with you to appointments.	6	7		
A	The way the actually helped me along and connected with my doctor.	6	14		
A	That I was able to contact the worker I had and get the support that I needed from them. She came to doctors appointments with me and help me ask the doctor questions.	6	14		
A	The rep comes with me to my doctor and helps get my health care back on track.	6			
A	They helped the doctor to help examine me in the right way.	6			
A	When the nurse was with me and defended me dealing with the doctor that was not being fair - I liked that.	6			
A	They follow up with care and the nurse also helps me get into special programs.	7	15		
A	I like how they call and check on me and see how I am doing and if I need anything done.	7			
A	That they cared enough to call and check in on me. They asked if I need any additional help.	7			
A	They call and check on me to see if I need help in any kind of way.	7			
A	I liked that she came to my home to speak to me. I didn't have to secure a ride or go to her office. She made about 4 out of 7 scheduled appointments.	8			
A	That the nurses come to my house.	8			
A	The help coming to your house to talk with me	8			
A	I really liked the face-to-face meetings with the care nurses.	8			
A	They have provided me with information about resources that I have needed.	9	18		
A	The nurse's help in referring me to different sources.	9			
A	The resources.	9			
A	The case management with the nurse.	10			
A	One of the things that really sticks out for me is that they taught me how to self-advocate. They did a lot of affirming of skills I do have and showed me how to retrain myself.	11	20		
A	I really enjoyed the initial introduction by the nurse and the social worker.	12			
A	It's comforting to feel that there is someone there to help when you get caught up in things that are happening that you don't understand.	13	19		
A	It was helpful for me	13			
A	KCCP helps you very well with everything.	13			
A	That knowing it was available and it really helped.	13			
A	That they are there to help me.	13			
A	The fact that I was eligible for it and am very grateful for their help.	13			

Group	What did you like best about the King County Care Partners Program?	Code 1	Code 2	Code 3	Code 4
A	The help that I got.	13			
A	They helped and provided for me.	13			
A	They really helped me out.	13			
A	The way they helped me out with things.	13			
A	What I liked the most - everything.	13			
A	That it was one-on-one - that I definitely felt that I was dealing with a person [redacted] - not just a bureaucracy. I felt she was looking out for my interests.	14	16		
A	The fact that I could belly ache about my health and they helped me get to the bottom of what was bothering me.	14	19		
A	The support that I received and to be able to talk to someone.	14			
A	The convenience.	17			
A	The amount of information that I received.	18			
A	They explained things very well to me and I am very satisfied with their response.	19			
A	I like the fact that they told me about things that I didn't know about. Gave me good information about my rights and I feel more confident.	20	25		
A	Nothing.	21			
A	It will work better for me in the future, but right now it is just OK.	23			
B	The nurse was friendly and seemed to really care about me.	1	2		
B	The nurse was very caring and went the extra mile to try to help me.	1	3		
B	I liked the support and the help that I received from the nurse [redacted].	1	14		
B	Cheerful and nice manner the nurse talked to me.	1			
B	I like the nurse who I was dealing with. Her name was [redacted].	1			
B	I liked the nurse that came out and talked with me.	1			
B	I really like her ability to help me with my needs.	1			
B	The nurse by the name of [redacted] who started with me was great. We got along very good. [Redacted] quit as she got in a dispute with her boss and then a person by the name of [redacted] came and she was very rude and we did not get along. She made several appointments with me broke several appointments and on the day she finally came she was 45 minutes late. Explained that she was late for the next appointment, only stayed 5 minutes and then left. [Redacted]'s replacement has contacted me but not made an appointment with me yet.	1			
B	The person that I had - her first name was [redacted].	1			
B	The nurse went above & beyond the call of duty. She wrote letters, phone calls, and was persistent and did not give up until she won.	3			
B	Some of the services.	15			

Group	What did you like best about the King County Care Partners Program?	Code 1	Code 2	Code 3	Code 4
B	She provided [me] with the medical information that I needed but something happened (she quit etc.) and I never received the shoes that she was going to bring me. I have never seen her replacement and this was in August.	18			
B	The information that I needed for my medical problems was provided.	18			
B	Nothing special.	21			
C	I like to be able to talk with the nurses and get answers to my questions.	1	19		
C	Really how nice the people were on the phone. And, how they explained things.	1	19		
C	The personnel were very helpful and answered questions.	1	19		
C	I like the nurses and the social workers that I have deal with.	1			
C	I liked the social worker who was very helpful.	1			
C	The nurse is very friendly and helpful and is easy to get along with.	1			
C	They were very friendly and very nice and tried to be very helpful.	1			
C	Informative that they were interested in my care.	2			
C	The nurse asked my doctor stuff that I could not ask and made sure that I got the information that I needed.	6	18		
C	The contact with me.	7			
C	Just the fact that I had a qualified nurse at my disposal to talk about any issue.	14			
C	It's pretty efficient.	17			
C	That they had information that they could give me about the dental work.	18			
C	They gave me some handout on health care and I thought that was interesting.	18			
C	Nothing.	21			
C	Nothing - they didn't do anything and they lied.	21			
C	Nothing.	21			
C	There wasn't anything.	21			
C	The KCCP has had a hard time getting together with me. I went to the doctors appointment at the wrong time, my cell phone was disconnected twice and we have just had a hard time connecting with each other.	22			
C	The nurse came and talked to me once and then met me at the doctors appointment once and since then I have not seen or heard from her.	22			
C	The hope that they were going to give me help with my health issues.	24			

Appendix E6. Open-Ended Responses: What Clients Liked Least About KCCP

Question

What did you like least about the King County Care Partners Program?

Legend

Group	Description	Total no. of clients asked this question	Total no. and % of clients who responded to this question	Total no. of response codes
A	Completed care plan, still participating or participated as long as they wanted	105	66 (63%)	69
B	Completed care plan, didn't participate in program as long as they wanted	16	14 (88%)	14
C	Agreed to participate, didn't complete care plan	33	20 (61%)	21
Total		154	100 (65%)	104

Coding Summary across Groups

Code	Major themes	Group A n ³⁶ = 66 n ³⁷ %		Group B n = 14 n %		Group C n = 20 n %		Overall n = 100 n %	
	Miscellaneous								
1	There was nothing I didn't like.	46	70	3	21	9	45	58	58
2	Refused to answer	0	0	0	0	1	5	1	1
	Process/Program								
3	I was disappointed that my first nurse left or nobody ever followed up with me after my first nurse left.	1	2	3	21	0	0	4	4
4	The program ended too soon or too abruptly.	0	0	2	14	2	10	4	4
5	They came to appointments when I didn't want them to, or called too often.	0	0	1	7	2	10	3	3
6	There was not enough follow-up.	1	2	1	7	0	0	2	2
7	It takes too long to get resources.	2	3	0	0	0	0	2	2
8	It was not well-organized.	1	2	1	7	0	0	2	2
9	There was too much paperwork.	1	2	0	0	0	0	1	1
10	There was too much focus on my mental health.	0	0	1	7	0	0	1	1
11	The meetings were too long.	1	2	0	0	0	0	1	1
12	We had a disagreement about pain medications.	1	2	0	0	0	0	1	1
13	It was impersonal.	1	2	0	0	0	0	1	1
14	I did not like communicating over the phone.	1	2	0	0	0	0	1	1
	Lack of Services								
15	I did not get the help or services that I needed.	7	11	2	14	1	5	10	10
16	I did not get help with housing.	1	2	0	0	1	5	2	2
17	They won't pay for my medications.	1	2	0	0	0	0	1	1
18	I don't know what services they offer.	0	0	0	0	1	5	1	1
	Staff								
19	The staff were rude/loud/bossy/pushy/judgmental/inflexible.	2	3	0	0	2	10	4	4

³⁶ n represents the number of people in that group who provided a response to this open-ended question.

³⁷ n represents the number of clients whose comment was coded under that theme. For example, 46 clients in Group A made comments suggesting that there was nothing they didn't like.

		Group A n ³⁸ = 66 n ³⁹ %		Group B n = 14 n %		Group C n = 20 n %		Overall n = 100 n %	
Code	Major themes								
20	They didn't give me the facts I needed.	0	0	0	0	1	5	1	1
21	They didn't serve as advocates.	1	2	0	0	0	0	1	1
22	They didn't come to my provider's appointment.	0	0	0	0	1	5	1	1
23	They were not very experienced with disabilities.	1	2	0	0	0	0	1	1

[illegible]

Group	What did you like least about the King County Care Partners Program?	Code 1	Code 2
A	Nothing.	1	
A	Nothing.	1	
A	Nothing went wrong.	1	
A	Nothing.	1	
A	Nothing.	1	
A	Nothing.	1	
A	Nothing. Overall happy.	1	
A	Nothing.	1	
A	They were great.	1	
A	My first nurse, [redacted], was fired and I really liked her and that made me disappointed. But now that I've met my new nurse, I like her too.	3	
A	She came only once, and promised to come back but she never came.	6	
A	It took a bit too long to get some things rectified - she tried her hardest but some of my needs weren't getting met - I thought they would be.	7	15
A	That it has taken such a long time to get connected with the resources that are offered with the nursing care. But, they are trying.	7	
A	My nurse was a tender and kind person - very compassionate - but not very well organized and maybe not very experienced with people with disabilities. She was not good at accessing services for me.	8	23
A	I was swamped in paperwork! Almost too much.	9	
A	The meetings with the nurse were a little lengthy and I had someone waiting in the car for me.	11	
A	It's the fact of the doctors trying to agree in my case. I take a lot of medications and I have talked to them that some of the medications are not good for me. They had the possibility of helping me but really didn't help me. Because, in my case, the doctors complained that I take too much pain medication. I have been in pain for 16 years. I told them that what takes away my pain is marijuana. They won't prescribe that since they seem [to think] I take too much meds. I am now going through a third party to get the marijuana that I need. The extreme pain makes me go to the Emergency Room and I need the pain medication!	12	
A	I wish it [was] more personal.	13	
A	Having to talk on the phone.	14	
A	Medically, I would wish they would have more control in being able to help the patient be guided to the correct facility if your regular doctor couldn't help. Also, serve as a client advocate.	15	21
A	I need some dentures and need help getting them.	15	
A	Not being able to have the nurse keep up with the seriousness of the illness that I had.	15	
A	That they can't help around the house or check me out around the house.	15	
A	The nurse came to all of my appointments and now will not help me get another doctor.	15	
A	Wasn't a lot they could do.	15	
A	Couldn't provide low income housing help in my community. Did sign me up for low income house but it didn't help.	16	
A	Initially, they helped me pay for medications, but now they won't pay.	17	
A	The way they were so pushy.	19	
A	Nurse was uncooperative in dealing with my wife.	19	
B	Nothing.	1	
B	Nothing.	1	
B	Nothing.	1	

Group	What did you like least about the King County Care Partners Program?	Code 1	Code 2
B	I am disappointed that [redacted] - my nurse - was let go. I had excellent rapport with her.	3	
B	I did not like the idea that you built a relationship with a person (nurse or social worker) and then all of a sudden that stopped and you never heard anything for a long time.	3	
B	That the other lady didn't call me. First person was great, but nobody followed through when she left.	3	
B	I was upset that it ended for me.	4	
B	It ended too soon.	4	
B	That they called so often.	5	
B	I wish I would have had more visits from the nurse. There was not enough of them.	6	
B	Lack of organization and proper follow through.	8	
B	I felt that she was there to check out the mental health portion of me and that is not what I needed. That she referred to me as a high user of medical services and that was not the true. Once she got my records, that issue never came up again.	10	
B	Not being able to get the help I needed.	15	
B	When I was dealing with the nurse, she was helpful, but not necessarily some of the programs.	15	
C	Nothing.	1	
C	Nothing.	1	
C	Nothing.	1	
C	Nothing.	1	
C	Nothing.	1	
C	Nothing.	1	
C	Nothing.	1	
C	Nothing.	1	
C	Nothing.	1	
C	Nothing.	1	
C	My expectations were high and I can't answer that.	2	
C	They cut me off as soon as I got a job that does not offer medical insurance coverage.	4	
C	They dropped me.	4	
C	I really don't understand why the nurse wants to go to the doctor with me all the time.	5	
C	Sometimes I did not want the nurse to come to my appointments but she did.	5	
C	Didn't have the services I needed.	15	
C	They gave me the expectation that they could help me with housing and they couldn't. Section 8 was closed and I was still in the same waiting line for HUD. I agreed to let the nurse come to my provider appointment, but she was never available to do that.	16	22
C	Not knowing exactly what they offer or can do for me.	18	
C	The nurse is a little bossy and loud.	19	
C	The nurse that came to see me was very judgmental. She was very rude and she insisted that I do it her way.	19	
C	I did not like the person that I was talking to, because they did not give me the facts that I needed.	20	

Appendix F. Client Satisfaction as Measured by the CSQ-8 for Clients with High, Medium, and Low Participation Levels in the RTC Program

Variable	Participation Level						Overall n =154 n %	p-value ⁴⁰
	High n = 105 n %		Middle n = 16 n %		Low n = 33 n %			
How would you rate the quality of service you have received?								<.0005
Excellent	73	70	8	50	8	28	89	59
Good	24	23	6	38	10	34	40	27
Fair	6	6	2	13	7	24	15	10
Poor	2	2	0	0	4	14	6	4
Missing values	0		0		4		4	
Did you get the kind of service you wanted?								<.0005
No, definitely	2	2	0	0	4	13	6	4
No, not really	5	5	1	7	6	20	12	8
Yes, generally	30	29	7	47	13	43	50	34
Yes, definitely	67	64	7	47	7	23	81	54
Missing values	1		1		3		5	
To what extent has our program met your needs?								<.0005
Almost all of my needs have been met	52	50	5	31	5	17	62	41
Most of my needs have been met	33	32	5	31	4	13	42	28
Only a few of my needs have been met	16	15	5	31	8	27	29	19
None of my needs have been met	3	3	1	6	13	43	17	11
Missing values	1		0		3		4	
How satisfied were you with the amount of help you have received?								<.0005
Quite dissatisfied	1	1	0	0	8	29	9	6
Indifferent or mostly dissatisfied	5	5	1	7	5	18	11	8
Mostly satisfied	25	24	5	36	9	32	39	27
Very satisfied	73	70	8	57	6	21	87	60
Missing values	1		2		5		8	
Have the services you received helped you deal more effectively with your problems?								<.0005
Yes, they helped a great deal	57	55	6	38	5	18	68	46
Yes, they helped	39	38	8	50	7	25	54	37
No, they really didn't help	6	6	2	13	14	50	22	15
No, they seemed to make things worse	1	1	0	0	2	7	3	2
Missing values	2		0		5		7	
In an overall general sense, how satisfied are you with the service you received?								<.0005
Very satisfied	70	67	6	38	9	30	85	57
Mostly satisfied	25	24	7	44	11	37	43	29
Indifferent or mildly satisfied	7	7	3	19	4	13	14	9
Quite dissatisfied	2	2	0	0	6	20	8	5
Missing values	1		0		3		4	
Did the program meet your expectations?								<.0005
Exceeded expectations	36	35	3	19	1	3	40	27
Met many of my expectations	43	41	6	38	7	24	56	38
Met a few expectations	22	21	6	38	7	24	35	23
Did not meet my expectations	3	3	1	6	14	48	18	12
Missing values	1		0		4		5	

⁴⁰ p-value calculated using Fisher's exact test

Appendix G. Demographic, Other Descriptive, and EQ-5D Variables by Subgroup

	Group A <i>n</i> = 105 <i>n</i> %		Group B <i>n</i> = 16 <i>n</i> %		Group C <i>n</i> = 33 <i>n</i> %		Total <i>n</i> = 190 <i>n</i> %		P-value ⁴¹
Gender									NS ⁴²
Male	40	38	4	25	13	39	57	37	
Female	65	62	12	75	20	61	97	63	
Age group									NS
20-39	16	15	3	19	4	12	23	15	
40-49	32	30	9	56	7	21	48	31	
50-59	48	46	2	13	17	52	67	44	
60-85	9	9	2	13	5	15	16	10	
Race/ethnicity									NS
White	54	51	10	63	21	64	85	55	
Black	36	34	5	31	8	24	49	32	
Other	15	14	1	6	4	12	20	13	
Mental illness flag									NS
High	55	52	6	38	15	45	76	49	
Low	44	42	10	63	16	48	70	45	
None	6	6	0	0	2	6	8	5	
Needs treatment flag									NS ⁴²
No	60	57	8	50	16	48	84	55	
Yes	45	43	8	50	17	52	70	45	
Co-occurring mental illness and SUD									NS ⁴²
No	63	60	8	50	18	55	89	58	
Yes	42	40	8	50	15	45	65	42	
Co-occurring mental illness (high) and SUD									NS
No	76	72	12	75	27	82	115	75	
Yes	29	28	4	25	6	18	39	25	
Co-occurring mental illness (low) and SUD									NS
No	92	88	12	75	24	73	128	83	
Yes	13	12	4	25	9	27	26	17	
Risk score									NS
1.5 - 1.99999	44	42	9	56	16	48	69	45	
2.0 - 2.4999999	34	32	4	25	9	27	47	31	
2.5 and over	27	26	3	19	8	24	38	25	
Would you say that in general your health is...									NS
Excellent	4	4	0	0	0	0	4	3	
Very good	10	10	1	6	1	3	12	8	
Good	21	20	1	6	6	18	28	18	
Fair	39	37	7	44	10	30	56	36	
Poor	30	29	7	44	16	48	53	34	
Don't know / Not sure	1	1	0	0	0	0	1	1	
Which statement best describes your mobility?									NS
I have no problems walking about	22	21	4	25	10	31	36	24	
I have some problems walking about	79	76	10	63	22	69	111	73	
I am confined to bed	3	3	2	13	0	0	5	3	

⁴¹ p-value calculated using Fisher's exact test, unless otherwise noted

⁴² p-value calculated using chi-square test

	Group A <i>n</i> = 105 <i>n</i> %		Group B <i>n</i> = 16 <i>n</i> %		Group C <i>n</i> = 33 <i>n</i> %		Total <i>n</i> = 190 <i>n</i> %		p-value⁴³
Which statement best describes your self-care?									NS
I have no problems with self-care	57	55	8	50	19	58	84	55	
I have some problems washing or dressing myself	43	41	5	31	12	36	60	39	
I am unable to wash or dress myself	4	4	3	19	2	6	9	6	
Which statement best describes your usual activities (e.g. work, study, housework, family, or leisure activities)?									NS
I have no problems with performing my usual activities	24	23	5	31	7	21	36	24	
I have some problems with performing my usual activities	63	61	7	44	19	58	89	58	
I am unable to perform my usual activities	17	16	4	25	7	21	28	18	
Which statement best describes your pain or discomfort?									NS
I have no pain or discomfort	12	12	1	6	3	9	16	10	
I have moderate pain or discomfort	49	47	10	63	15	45	74	48	
I have extreme pain or discomfort	43	41	5	31	15	45	63	41	
Which statement best describes your anxiety or depression?									NS
I am not anxious or depressed	23	22	3	19	10	30	36	24	
I am moderately anxious or depressed	50	48	9	56	17	52	76	50	
I am extremely anxious or depressed	31	30	4	25	6	18	41	27	
Do you have a personal doctor?									NS
No	3	3	2	13	2	6	7	5	
Yes	102	97	14	88	31	94	147	95	
In the last six months, how often did you an appointment for your healthcare at a doctor's office or clinic as soon as you thought you needed?⁴⁴									.027
Never	2	2	0	0	4	13	6	4	
Sometimes	20	19	4	29	6	19	30	20	
Usually	15	14	1	7	9	28	25	17	
Always	68	65	9	64	13	41	90	60	

⁴³ p-value calculated using Fisher's exact test, unless otherwise noted

⁴⁴ Entire text of question was "In the last six months, not counting times you needed care right away, how often did you get an appointment for your healthcare at a doctor's office or clinic as soon as you thought you needed?"